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**Stroke and self-identity among people of advanced older age
A biographical approach**

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**Stroke and self-identity among people of advanced
older age: A biographical approach**

THESIS
presented for the
DEGREE
of
DOCTOR OF PHILOSOPHY
Medical Sociology

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Abstract

Stroke is one of the leading causes of adult disability, but little is known about the meanings of stroke for survivors of advanced older age. This thesis examines the experience and meaning of stroke in relation to the self-identity of people aged 75 and over based on a biographical-narrative approach. It draws on both Giddens's (1991) conceptualisation of self-identity as a set of reflexive biographical narratives and Goffman's (1959) notion of identity as constructed in everyday social interaction.

Individual and joint biographical-narrative interviews were conducted with 27 stroke survivors and 13 spouses, aged 75 and over. Three forms of analysis were employed, to examine both narrative content and narrative style, namely thematic analysis, analysis of interaction in joint interviews and linguistic methods involving comparative key word analysis.

Thematic analysis demonstrated the significance of an individual's whole biography for meanings assigned to stroke and processes of narrative reconstruction with other overarching themes and aspects of self-identity identified as employment, loneliness and bereavement; and housing and community. Underlying these themes were self-presentations as hardworking, honest and financially self-sufficient, thus resisting dominant negative discourses associated with old age and ill health.

Analysis of interaction and language in couple interviews led to the identification of three types of relationship that shaped the meaning of stroke. 'United couples' pulled together and emphasised their accommodation of the stroke and normality as a couple, despite often considerable disability, and was strongly underpinned by a collaborative narrative style; 'Positive caring relationships', described self-reliant couples who took pride in how they managed, and 'Frustrated carers' emphasised the difficulties of caring and hardships experienced and were characterised by a conflictual narrative style. These data extend notions of how illness is 'lived' and demonstrate how biography and marital relationships can mediate the experience of chronic illness and its impact on identity.

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Chapter 1: Literature Review: Identity, old age and chronic illness

Introduction

This thesis examines the experience and meaning of stroke in relation to the self-identity of people of advanced older age. Chapter One provides a review of the literature on old age and chronic illness in relation to identity and outlines the theoretical framework for this thesis. Chapter Two provides a review of the literature examining the co-construction of narratives in joint interviews and sociolinguistic studies on the use of language in interaction. Chapter Three details the methods that involved conducting biographical narrative interviews which were analysed using three forms of analysis. Chapter Four presents findings focusing on analysis of the narrative themes of self-presentation and describes differing components of older people's self-identity, Chapter Five presents findings on the co-construction of narratives in the joint interviews and types of narrative style, Chapter Six presents findings based on the sociolinguistic analysis of interview data. The final discussion chapter integrates and discusses the findings and provides recommendations for further research and policy and practice.

First, this chapter provides a context for the thesis, giving an overview of the socio-demographic characteristics of the older population in the UK in relation to chronic illness and in particular the nature and prevalence of stroke. Second, the main theories of social identity and ageing are presented to provide an understanding of societal attitudes towards older people and the ways in which these have changed over time. Third, a discussion of two key theories on identity provides the theoretical framework for this thesis. Fourth, key theories of social identity and old age are examined before reviewing studies that draw on these theories to understand the implications for identity amongst older stroke survivors and to identify gaps in the empirical literature. Fifth, a critical review of the literature on chronic illness from a biographical perspective is presented to understand what is known about the experience and meaning of chronic illness in older age. Finally, the gaps in the literature on the experience of chronic illness and on identity and older age are summarised, providing a clear rationale for the focus of this thesis.

Characteristics of the ageing population

The population is ageing due to higher birth rates after the Second World War, lower fertility rates after 1960s, and an increase in life expectancy due to medical advances over the twentieth century. There are 5.2 million people aged 75 years and over living in the UK and this is projected to rise by 89.3%, to 9.9 million, by 2039 (Office for National Statistics 2008, 2014). Three conflicting hypotheses have been proposed about future trends in morbidity amongst older people, including arthritis, heart conditions and stroke. The first predicts that due to medical advances and changes in lifestyle an increase in life expectancy would lead to a 'compression of morbidity' (Fries 1983). This refers to an increase in the number of years people live in good health and a decrease in the number of years with morbidity and disability suggesting a 'terminal drop' at the very end of life. National survey data in the US has been used to demonstrate a decline in levels of disability, referring to loss of function (Fries, 2005). However the second 'expansion of morbidity' hypothesis (Gruenberg 1977) suggests that increased life expectancy has led to an increase in the number of years of ill health due to the successes of medicine keeping older people alive who would previously have had terminal conditions. It is argued that medicine has been successful in intervening in a large number of what were terminal illnesses, however medicine has not ended chronic conditions that rise in their place and so there is an increase in disability. 'The postponement of morbidity' (Manton, Stallard et al. 1995) is a third hypothesis that proposes that the increase in life expectancy has been accompanied by a comparable postponement of chronic illness and disability. Therefore disability rates will remain approximately the same as they were at the end of the twentieth century although disability as a proportion of the life course will reduce. Data from different sources can be found to support each of these three hypotheses (Fine 2007). UK statistics indicate a gradual increase in the number of years people spend in poorer health. In 1981, from birth men could expect to live an average of 12.8 years with a limiting illness which rose to 15 years in 2009-2011 and for women this was 16 years in 1981 rising to 18.4 years in 2009-2011 (Office for National Statistics, 2008, 2014).

Many older people are living with multimorbidity, such as diabetes, heart conditions and stroke. One study based on data from a random sample of nearly 100,000 patients in England from the General Practice Research Database found that 44% of patients aged 75 years and over had multimorbidity, based on definitions used by the Quality Outcomes Framework (Salisbury, Johnson et al. 2011). In addition the number of people aged 75 and over with disabilities is predicted to rise by 85% from 1.37 million people in 2007 to 2.53 million people in 2032 (Pickard, Wittenberg et al. 2012) which has important implications in terms of provision of health and social care.

In the UK 6.5 million people are carers for older, chronically ill and disabled people; almost 1.3 million of these carers are aged 65 and over (Carers UK 2015), although no data is available for those aged 75 and over. Informal care refers to help with personal care, such as washing and dressing, or domestic tasks, such as cooking and cleaning, from relatives or friends, provided because of the disability of the care recipient (Pickard, Wittenberg et al. 2012), and also social and emotional care. Most of those aged 75 and over receiving informal care receive it from a child or spouse/partner. For this age group the numbers receiving care from a spouse is predicted to increase by 133%, from 250,000 people in 2007 to 580,000 in 2032, which is more than double the rate at which care by a child will increase (Pickard, Wittenberg et al. 2012). Often older spouses who are carers are also living with their own health conditions, such as diabetes and arthritis (Pickard, Wittenberg et al. 2000), with older couples often having an interdependent caring relationship.

Stroke survivors are among those who may often have to rely on informal care from spouses and other relatives as many are left with disabilities that mean they are unable to live independently. One in five dependent stroke survivors in the UK are cared for by family and friends (Stroke Association 2016). Stroke is one of the leading causes of adult disability in England, with half of all stroke survivors living with a disability (Stroke Association 2016). There are over 1.2 million stroke survivors in the UK, according to Quality and Outcomes Framework data (Stroke Association 2016). Each year there are over 152,000 strokes in the UK, with age being the single most important risk factor (Stroke Association 2016). By the age of 75, 1 in 5 women and 1 in 6 men will have a stroke (Seshadri, Beiser et al. 2006). Over three per cent of all men aged 75 and over (3.5%) and just over 2 per cent of all women aged 75 and over (2.1%) are living with stroke in Britain (General Household Survey, Office for National

Statistics, 2006). People from the most economically deprived areas of the UK are approximately twice as likely to have a stroke as those from the least deprived (Stroke Association 2016).

Becker and Kaufman describe stroke as 'an assault on the body- the "natural", "right" sense of self' (1995: 168) as it can impact on virtually all human functions, such as ability to carry out basic activities of daily living, cognition, speech and mood. Stroke causes a greater range of disability than any other condition (Adamson, Beswick et al. 2004). Stroke can affect walking, talking, speech, balance, co-ordination, vision, spatial awareness, swallowing, bladder control and bowel control and many stroke survivors experience fatigue, anxiety and depression (Stroke Association 2016). A review of qualitative studies on adjustment after stroke points out that stroke can cause a variety of physical and cognitive impairments, some of which may not be obvious to an outsider, such as fatigue and anxiety, and suggests that stroke can have a profound effect on stroke survivors' sense of self and on their relationships (Sarre, Redlich et al. 2014). A recent UK survey of over 2,700 people affected by stroke revealed that nearly half of stroke survivors reported that their relationships with friends and family had been put under strain and two thirds of carers who were spouses or partners reported experiencing difficulties in their relationship with the stroke survivor (Stroke Association 2013).

Unlike other chronic conditions, the impact of stroke is sudden leaving the individual and their family unprepared to deal with the consequences. Patient outcomes have significantly improved as a result of the recent reorganisation of UK stroke services since 2005 under the Department of Health's strategy for stroke care (National Audit Office 2010). Stroke patients' chances of dying within ten years of a first stroke are estimated to have reduced from 71 to 67 per cent since 2006, with the result that there are higher numbers of stroke survivors living with disability (National Audit Office 2010). Stroke management now involves rapid assessment and admission, and thrombolysis (clot busting drugs) is a key intervention for acute ischaemic stroke that can reduce disability from stroke if it can be administered within four and a half hours (Robinson 2011, Stroke Association, 2016). However thrombolysis is only licensed to be used in adults aged under 80 years because older people have been excluded or only partially represented in clinical trials (Zaheer, Robinson et al. 2011) (National Institute for Health and Care Excellence 2012). Although physical improvement

usually occurs mainly within 3-6 months, stroke is often experienced as an uncertain illness trajectory in old age (Becker and Kaufman 1995). Treating stroke presents a particular challenge to the medical profession as there is no cure.

Patients are now mainly treated in specialist stroke units. Most hospitals in England now have such a unit, although the services provided and length of stay in the units vary. Improvements in follow-up care from health and social care services have been at a slower rate than improvements in acute hospital services, with a third of patients not getting a follow-up appointment within six weeks of hospital discharge (National Audit Office 2010). However since 2011 improvements have been made and in 2015 approximately 32% of stroke patients in England, Wales and Northern Ireland were discharged with early supported discharge services which are designed for stroke survivors with mild to moderate disability who can receive the necessary rehabilitation at home (Royal College of Physicians 2004).

National data on the living arrangements of stroke patients are not available, however, locally the South London Stroke Register (SLSR) gathers this data in addition to other demographic data. The SLSR is an ongoing population-based register established in 1995 at King's College London (Wang, Rudd et al. 2013). SLSR participants are identified, through multiple notification sources, to be included on the register at the time of their stroke (Stewart, Dundas et al. 1999). There are approximately 4,000 living patients currently registered and participants are followed up by a fieldworker administering a questionnaire (or a postal self-completion questionnaire) at three months post stroke and then annually. Based on SLSR data from 2016, prior to the stroke most stroke survivors had lived in private households alone (34.2%) and with others (55.1%), with a small proportion living in sheltered housing (4.7%), residential homes (0.8%) and nursing homes (1.2%). One year after stroke the proportion of stroke survivors who lived in private households alone had decreased (27.8%) and those living with others had decreased slightly (53.2%), while the proportion who lived in sheltered housing (5.2%) and residential homes (2.2%) had slightly increased. However the largest increase was in the proportion living in nursing homes (6.7%) one year post stroke, which is likely to reflect the high level of physical dependency of some stroke survivors.

Understanding societal attitudes to older people

Historically older people have largely been homogenised as a group characterised as experiencing poor health and being economically and socially dependent on the state. However the theory of structured dependency (Townsend 1981) argued that older people's economic and physical dependency has been socially constructed over the twentieth century. This was due to the legitimisation of low income for older people, residential institutions for older people that served as a means of social control, community care services aimed at 'passive' older people and the imposition of earlier retirement. Although retirement has been largely regarded as a social achievement, it was argued that this was a form of mass redundancy designed to serve a modern capitalist economy, with many older people who were able to continue working and wished to do so being forced to retire. Greater value was attached to younger workers; older people living with illness and disability, including stroke, received less support than those who were younger. Connected with this were low rates of state pension that meant many older people lived in poverty due to less access to resources such as paid employment. Disability in old age as a result of ill health, including stroke, also restricted access to resources and led to added costs. The low status that older people held within society over the twentieth century was in stark contrast with the status that older people had within the family, where they were often treated with respect and fulfilled valued roles, for example many older women contributed to childcare (Townsend 1981).

Further developing the theory of structured dependency, it has been argued that in the second half of the twentieth century the institution of retirement was destabilised due to a slow-down in economic growth and a rise in unemployment and inflation in the 1970s, and together with the decrease in the ratio of people of working age to older people in the population, spending on welfare in Western countries began to be questioned (Phillipson 1998). This led to notions of older people as a burden on society in terms of the high costs of providing state pensions and health care. These changes led to a significant shift in the identity of older people as more socially marginalised and vulnerable, facing insecurity about their place in a capitalist society where identities are strongly linked to the roles of producer and consumer (Phillipson 1998).

These critical gerontological perspectives illustrate the ways in which older people have been socially constructed as passive, dependent welfare recipients over the twentieth century and were therefore perceived as a 'social problem'. These arguments have particular relevance for understanding the identity of older stroke survivors who may feel even more marginalised and vulnerable due to ill health and disability. The experiences of employment and retirement are likely to be particularly important to identity in older age, within the context of ageing in a capitalist society where identities are strongly connected to the roles of producer and consumer. Phillipson (1998) points to the importance of empirically studying identity in older people and it would be useful to examine the applicability of his arguments concerning both self and social identity of older people in an empirical study. However it can be argued that focusing on the economic and social disadvantage experienced by older people, tends to homogenise older people and underestimates the increasing diversity within the older population.

An alternative to critical gerontological perspectives was offered by Laslett (1989), who was writing when affluence amongst older people was increasing due to a rise in standards of living. He emphasised the greater heterogeneity of older people due to profound changes in the stages of the lifecourse. After the 'first age' (the stage of socialisation during childhood and adolescence) and the 'second age' (the period of life spent in paid employment and child rearing), he argued that the 'third age' is an emerging period in the lifecourse between middle age and old age (Laslett 1989). This is the period of retirement viewed as a positive, independent and fulfilling stage, to be looked forward to after the responsibilities of paid employment and child rearing are over. The emergence of this new life stage is attributed to improved health in older age and an increase in earnings and private pension schemes from the 1980s onwards. This has provided many retired people with more agency than previous generations, particularly greater consumer power, challenging traditional notions of old age. In contrast to the 'third age', the 'fourth age' is a period of old age characterised by serious illness, functional decline, frailty and physical dependence (Laslett 1989), in line with the notions of older age put forward by the conflict perspectives (Townsend 1981, Phillipson 1998). These stages are defined in relation to socio-economic resources, health and independence rather than chronological age. The 'fourth age' does not necessarily chronologically follow 'the third age', and some people may well not enter the 'the third age' but instead go straight to 'the fourth

age', particularly those who have fewer economic resources and poorer health. I would argue these life stages are useful typologies, although distinctions between the third and fourth age may become blurred in reality and, as critics have pointed out, it is also possible for people to move in and out of 'the fourth age' depending on fluctuations in their health and mobility (Midwinter 2005).

More current thinking, in line with a postmodern perspective, extends Laslett's (1989) notion of 'the third age' to emphasise the role of older people's agency and the increased consumer power of this group and the engagement in an active consumer lifestyle (Gilleard and Higgs 2005). Gilleard and Higgs (2005) argue that third agers have increased opportunities to develop multiple identities, resisting traditional stereotypes of older people as having a lack of autonomy and agency and as socially and economically marginalised, as portrayed by critical gerontological perspectives (Townsend 1981, Phillipson 1998). Certain shared socio-economic and cultural developments have had a huge impact on the lives of the baby boom post war generation that meant they were more likely to experience 'the third age'. These include increased availability of education, higher earnings, greater material security, a rise in public consumption, more leisure time, and increased personal freedom. Although the focus on the lifestyle and consumerism of older people in the third age (Gilleard and Higgs 2005) had meant that the fourth age was under-theorised, more recent work has begun to address this (Gilleard and Higgs 2010, Gilleard and Higgs 2011). Gilleard and Higgs further develop Laslett's (1989) notion of the fourth age, viewing it as 'a kind of distortion in the mirror of the third age' (2010: 122), and associate it with a loss of agency and reflexivity that are key in the experience of the third age. However rather than viewing the fourth age as a stage of life, as Laslett (1989) did, they conceptualise it as 'a kind of terminal destination- a location stripped of the social and cultural capital that is most valued and which allows for the articulation of choice, autonomy, self-expression and pleasure in later life' (Gilleard and Higgs, 2010: 123). For them the fourth age is a social and cultural 'black hole' that represents the death of the social, from which there is no return.

However the application of the concepts of the third and fourth age in empirical research is a relatively new area of interest to sociologists and gerontologists. This is a gap that this thesis begins to address with its focus on stroke survivors aged 75 and over. While those of advanced older age born before the war, living in

economically deprived inner city areas, living with at least one chronic condition are perhaps less likely to experience an old age in line with the 'third age', their experiences of old age will perhaps not necessarily reflect Gilleard and Higgs' (2010) bleak conceptualisation of 'the fourth age' as a social and cultural black hole.

Despite the rise in the consumer power of older people in the 'third age', current perceptions of older people in modern society are dominated by many negative images and stereotypes. Older people are often viewed as a homogenous group, presumed to be socially isolated, in poor health and passive and dependent recipients of health and social care services, with retirement from paid employment often viewed as having negative consequences (Victor 2005). For example, a review of studies on public perceptions of older people from 1989-2009 found that negative perceptions tended to dominate with older people often stereotyped as having poor health, with diminishing mental ability, unattractive, lonely and excluded from society (Drennan, McNamara et al. 2009). Victor (2005) argues that current stereotypes of ageing encourage us to ignore the old in society because they are a non-productive group in a society that emphasises the roles of productivity and dependence, echoing Townsend's (1981) arguments nearly a quarter of a century earlier. Victor (2005) suggests that these very negative and pervasive stereotypes are evidence of ageism, referring to the systematic stereotyping and discrimination of older people because they are of a particular age (Butler 1969). She points out that ageism is widely thought to exist within health and social care systems, citing the first standard of the National Service Framework for Older People as aimed at combating ageism in relation to access to services and quality of care (Department of Health 2001). Victor (2005) argues that these negative images may pervade the self-identity of older people who may accept the stereotype of age and become disengaged, passive, grateful recipients of welfare benefits and health and social care services, making the stereotype a reality. This raises the question of how relevant these negative societal attitudes and images may be to the self-identity of older stroke survivors, bringing us to the next section on self and identity, followed by a discussion of identity in relation to older age.

‘Identity’ and the ‘self’

‘Identity’ is not easily defined and has been conceptualised in various ways by psychologists and sociologists. A single overarching definition of identity is not possible as the meaning of identity is dependent on how it is theorised (Lawler 2015). A conceptual distinction has been made between ‘identity’ and ‘self’ (Kelly 1992; Kelly and Millward 2004). ‘Identity’ is perceived as the public knowable aspect of the person, constructed through everyday social interaction whereas the ‘self’ is conceptualised as the inner private self, unique to an individual. Identity is described as the way we are known and constructed as social beings during interaction with others. This conceptualisation of identity relates to Goffman’s (1959) symbolic interactionist perspective of identity as constructed through everyday social interaction. In contrast, the inner ‘self’ has a certain amount of stability and continuity but also has the capacity to change, constantly being rehearsed, constructed and reconstructed. Reflexivity is a critical aspect of the self and the ability to take the standpoint of others in imagination, referred to as the process of role-taking. This conceptualisation of the self is in line with Giddens’ (1991) notion of the self as a set of reflexive biographical narratives. I now discuss each of Goffman’s (1959) and Giddens’ (1991) approaches to identity, in turn.

Taking a symbolic interactionist approach, Goffman (1959) explored the construction of identity through ‘self-presentation’. He developed the analytical approach of dramaturgy, using the theatre as an analogy for everyday life. Social action is viewed as a ‘performance’ in which actors both play parts and stage manage their actions, seeking to control the impression they convey to others, referred to as impression management. For Goffman (1959) the components of the ‘front’ and ‘backstage’ make up the means for creating and maintaining selves. The public front region allows the scene of the performance to be constructed, enabling the actor to perform a social role, giving off verbal and non-verbal information, such as language, bodily gestures and appearance, that allows others to understand the actor. Individuals aim to construct an idealised front that legitimates their social roles and fits with societal norms. Examples of a social performance or ‘front’ may be participating in a research interview or a consultation with a doctor. In contrast ‘backstage’ refers to the areas where performances of a routine or role are prepared but are hidden from public view.

An example may be the kitchen of a restaurant where food is prepared hidden from the view of the customers.

Although writing nearly 60 years ago, Goffman's (1959) work is still particularly valuable for highlighting the significance of studying everyday language and interaction and the important role this plays in the construction of social identity, for example Scott's (2005) symbolic interactionist analysis of shyness in contemporary society draws on Goffman (1959). Goffman's approach has important implications in terms of the challenges older and chronically ill people may experience in self-presentation when trying to fit in with society's norms. His analysis of the construction of identity is particularly relevant to the experience of chronic illness and older age, as impression management of the 'front' stage is likely to become difficult for those whose appearance, mobility and social relationships are affected by chronic illness and older age. This may lead to the development of alternative approaches to impression management and alternative sources of identity construction, for example previous professional roles may be drawn on or roles within the family.

In contrast to Goffman's (1959) micro-level approach focusing on identity construction during everyday social interaction, Giddens (1991) structuration approach makes a link between the wider social structure and the self, or individual agency. He argues that social structures are created, maintained and changed through individual actions, while actions are given meaningful form through the background of social structure. Giddens (1991) argues that rather than living in a postmodern era, we are living in a post-traditional era, referred to as 'high' or 'late' modernity. He argues that global transformations brought about by modernity have led to profound changes in everyday social life, and one important change is an enhanced reflexivity at the level of both institutions and individuals. Institutions are regarded as achieving progress through the reflexive processes of reorganisation and ongoing evaluation. At the individual level, self-identity is regarded as a reflexive project to be continuously worked and reflected on. Giddens (1991) conceptualises self-identity as a set of biographical narratives referring to the story of who we are and how we came to be where we are now, that continually integrates life events in the external world. A stable self is based on an account of a person's life, actions and influences which make sense to them, and which can be explained to other people without much difficulty. It 'explains' the past, and is orientated towards an anticipated future,

forming a trajectory of development. The trajectory of the self has a coherence related to a cognitive awareness of the various phases of the lifespan. The life course is seen as a series of passages that the individual has to go through, for example, leaving home, starting a new relationship, confronting illness; these all mean running risks in order to grasp new opportunities which personal crises open up. The reflexivity of the self extends to the body where the body is part of an action system rather than merely a passive object, for example, monitoring of bodily dispositions and awareness of requirements of exercise and diet.

Giddens (1991) argues that ontological security is key to the development of self-identity. He describes ontological security as a 'protective cocoon'; a sense of 'invulnerability' which blocks off negative possibilities about the risks implied during everyday life, in favour of a generalised attitude of hope deriving from basic trust. The protective cocoon is essentially a sense of 'unreality' rather than a firm conviction of security: it is a bracketing of possible events, which could threaten bodily or psychological integrity. The protective barrier may be pierced, temporarily or permanently, by events which demonstrate the negative reality of risk (for example, driving past a serious traffic accident serves to remind people of their vulnerability and temporarily disrupts the protective cocoon). Giddens (1991) argues that rituals of trust and tact that are a part of everyday interaction, including language and bodily gestures that Goffman (1959) focuses on, are all part of maintaining ontological security. Routinised control of the body is crucial to sustaining an individual's protective cocoon in everyday interaction. This regularised control of the body is a fundamental means whereby a biography of self is maintained. Maintaining normal appearances, in line with a person's biographical narrative, is essential for feelings of ontological security. Following on from this argument, the experience of chronic illness, such as stroke, and its impact on the normal appearance and functioning of the body could present a significant challenge to ontological security.

Stroke can be considered to be what Giddens (1991) described as a 'fateful moment' referring to a transition point in life that has major implications for self-identity. This builds on his earlier concept of 'critical situations' referring to circumstances that may radically disrupt routines, traditions and institutions (Giddens 1979). Fateful moments can be regarded as consequential for a person's destiny and possibly problematic. They are times when an individual 'stands at a crossroads in his existence' (Giddens,

1991: 113) or where a person learns of information with fateful consequences. Examples include the decision to get married, the decision to take a job, receiving an illness diagnosis or experiencing an illness event such as a stroke. These events may threaten the protective cocoon which defends the individual's ontological security because the normal occurrence of everyday life has been disrupted. At fateful moments the individual is likely to recognise that he/she is faced with an altered set of risks and possibilities and may be faced with fateful decisions which, by definition, are difficult to take because they are both problematic and consequential. Experts are often brought in at the moment a fateful decision has to be made, for example medical experts. However individuals may also seek increased mastery of the circumstances themselves, dedicating time and effort to this, for example, seeking information and opinions in response to a medical diagnosis. I argue that stroke may be experienced as a 'fateful moment', presenting a significant challenge to a person's ontological security.

'Identity' (in line with Goffman's concept) is linked to the 'self' (in line with Giddens' theory) through social context and social relationships (Kelly 1992; Kelly and Millward 2004). Within macro and micro social structures people occupy positions, statuses and roles which signify how self is defined by others. Identities can be multiple and are situated in social terms. Particular identities defined with regards to social categories and relationships, such as gender, age, family and occupation, may have more or less salience for self and others depending on the social context. The self (also referred to as 'self-identity' in this thesis) and identity, overlap and reinforce one another but the experience of chronic illness can lead to tensions between the self and identity, bringing this dualism into question (Kelly and Millward 2004). Identity is constructed through social interaction and when a person experiences chronic illness there can be contradictions between these identities and how a person perceives and defines themselves which can lead to the questioning and reappraisal of the self (Kelly and Millward, 2004).

Many medical sociological studies have focused on the impact of illness for individuals in relation to both the self and identity, as discussed later in this chapter (see page 26). Although Giddens (1991) does not discuss the self in relation to chronic illness or older age in any detail, much of the sociological literature on the experience of chronic illness draws on a biographical framework linked to Giddens'

(1991) concept of the self as a set of reflexive biographical narratives that continually integrate life events, such as a stroke or death of a family member. Sociological studies have also examined the impact of chronic illness on carers, who are often spouses. However such studies have generally overlooked the perspective of both the person with chronic illness and their spouse together as a unit and the impact on their identity as a couple. More generally, although research in the areas of psychology and family studies has focused on couple identity, for example, Acitelli (2002) this is not an area that has been addressed in medical sociology. This will be discussed in Chapter Two in relation to the experience of chronic illness and narrative co-construction.

The link between the construction of self-identity and societal attitudes is complex but negative social identities of older people are prevalent in society and may pervade the self-identity of older people (Victor 2005). As discussed earlier in this chapter, current perceptions of older people in modern society are dominated by many negative images and stereotypes as a group who are socially isolated, in poor health and passive and dependent recipients of services. Older people may accept the stereotype of age and become disengaged, passive, grateful recipients of welfare benefits and health and social care services, making the stereotype a reality or may aim to resist these stereotypes and demonstrate identities associated with being active and independent. I now turn to a discussion of these issues in relation to the theoretical and empirical literature on identity in older age and consider the implications for identity amongst older stroke survivors.

Identity in older age

In modern British society, youth and aesthetic appearance are highly valued and ageing is generally perceived as something to be avoided or delayed at all costs. This raises the question of what it is like to be a person of advanced older age living today in British society and what implications this has for older people's identity. Although there is a small literature on identity and older age, there are a number of key theories. In this section I briefly discuss these themes before examining empirical studies that draw on these theories to inform this thesis on the identity of older stroke survivors.

From a postmodern perspective, it is argued that the threat to self-identity brought about by ageing is managed through the 'mask of ageing' (Featherstone and Hepworth 1989, Featherstone and Hepworth 1995). Ageing is seen to represent a threat to multiple and fluid identities as it becomes harder to 're-cycle' the body through cosmetics, surgery, props and prostheses, which leads to an internalised battle between a desire to express oneself and the ageing body. The ageing body becomes the source of barriers that prevent older people from participating in a consumer society and the different lifestyles that it offers. The mask of ageing is a contradiction 'between the fixedness of the body and fluidity of social images'. Core self-identity is seen as unchanging and trapped in an outer ageing body. However one major criticism of this theory is that it has not been developed in relation to any empirical data.

An alternative argument offered from a psychodynamic perspective, views the inner self as changing with age and 'masquerade' is seen as a way to manage this by attempting to maintain a self-identity in line with a society defined by values of youth and midlife (Biggs 1997, 2003, 2005). Ageing leads to tension between surface appearance and deeper elements of self-identity that are hidden from view. Drawing on the concept of a reflexive, managed self-identity (Giddens, 1991) in relation to the ageing self, 'masquerade' is defined as a managed performance that uses, for example, body language and forms of personal adornment. This performance is part of a coping strategy used by older people to maintain self-identity and present themselves as 'acceptable' ageing people (Biggs, 1997, 2003, 2005). 'Masquerade' is about attempting to achieve youthfulness on the outer surface while age is the inner experience. Although the concept of masquerade is not based on empirical data, Biggs (2004) recommends that future research should examine the performance of age identity in different settings and suggests that a focus on biography will contribute towards an understanding of age identity, providing support for a biographical narrative perspective in the study of older stroke survivors.

Although the theories of 'mask of ageing' (Featherstone and Hepworth, 1989, 1995) and 'masquerade' (Biggs, 1997, 2003, 2005) are not based on empirical research there have been a small number of empirical studies drawing on these perspectives. An interview study of older people (aged 70-92 years) who had been assessed as ineligible for support from UK social services showed that participants attempted to

maintain a positive sense of self as a way to manage unmet needs with two strategies being an emphasis on self-reliance and remaining as independent as possible (Tanner 2001). Information on the health of participants are not given but many found it difficult to carry out everyday tasks such as washing, dressing and cleaning, however the 'struggle' was itself viewed as having a positive value. Health was equated with continuing 'normal' living and participants' greatest struggle was often with tasks associated with self-identity such as appearance. Many preferred to rely on the state rather than their family to meet their financial, health and social needs as they did not want to be a burden. However in the 'helping relationships' that older people had with family, friends and neighbours, reciprocity, such as babysitting grandchildren or helping local charities, was important for maintaining selfhood. Maintaining a positive sense of self by developing both practical and psychological ways of coping was found to be a protective strategy or 'masquerade' (Biggs 1999) used by older people to resist threats from society to their core self-identity (Tanner, 2001). Although based on a small sample, participants' need to maintain a positive sense of self and remain as independent as possible are in line with findings of studies on older people's experience of chronic illness, discussed in the next section (see page 26). These studies also found that older people tended to minimise the impact of ill health, viewing it as a natural part of the ageing process (Pound, Gompertz et al. 1998, Faircloth, Boylestein et al. 2004) and were keen to present themselves as independent and not as a burden to society or their families (Sanders, Donovan et al. 2002).

An ethnographic study on the construction of social identity among residents of two separate sites (sheltered housing and a residential home) in Israel (Gamliel and Hazan 2006) also draws on Biggs' (Biggs 1997, Biggs 1999) notion of masquerade and on Goffman's (1963) concept of total institutions as sites of socialisation and identity construction. A total institution refers to a place of work and residence where similarly situated people are isolated from the wider community for a considerable time. Study findings demonstrate older peoples' ability to adapt despite often being stereotyped as homogeneous and passive by other residents. Clear distinctions were identified between the two groups of residents in the ways in which they engaged in identity construction. Older people living in the sheltered housing (mean age of 81, mainly from an upper-middle socio-economic background) displayed a denial of old age and distanced themselves from the stigma of old age through attempting to

reconstruct past identities and roles, often associated with previous employment reproducing status hierarchy. In comparison, those living in the home (mean age of 85, mainly from a lower-middle socio-economic background) engaged in in-group labelling and gossip as a way of distancing themselves from other residents, for example one woman was labelled as 'sick-bed' as she sat on her own and was deemed to be depressed. The authors argue that in different ways both groups were distancing themselves from other older people by engaging in a form of 'masquerade' (Biggs, 1997, 1999) as a tactical manoeuvre to protect themselves from the threat of social ageism. Differences in identity management amongst the two groups of residents were influenced by both individual characteristics and the living environment, with the residential home described as a more structured, depersonalised environment with higher levels of staff supervision compared to the more relaxed, private, homely feel of the sheltered housing. This study demonstrates the importance of the influence of housing and living environment on identity construction among older people which is strongly linked with socio-economic class, highlighting that experiences of old age can vary according to socio-economic class due to differences in access to resources and living environments.

This supports Gilleard and Higgs' (2002, 2005) work on the emergence of the 'third age' associated with older people's greater access to economic resources and increased consumer power, which contrasts with the 'fourth age' linked to socio-economic deprivation and poor health. This implies that living environment, socio-economic class and past employment will be important aspects to consider in this thesis on the experience and meaning of stroke for older people. However Gamliel and Hazan (2006) do not discuss the influence of health, as those living in the home may have been in poorer health and therefore more dependent which could have influenced the process of identity construction.

One study that has addressed health in relation to social identity in older age focused on the construction of age identity in a sample of 45 people aged 65 and over with at least one chronic condition, and a mean of five self-reported conditions (Rozario and Derienzis 2009). Drawing on a symbolic interactionist approach and the notion of stigma (Goffman, 1963), age identity was conceptualised as a social performance and three categories of age identities were identified: definitely old; definitely not old; and ambivalent about age. Those identifying as 'definitely old' experienced age as a

discontinuation of their middle age, particularly as they had experienced disabling chronic conditions and the death of a significant other. Participants categorised as 'definitely not old' associated this with feeling that they did not 'look old' and with a lack of 'aches and pains'. Those who were ambivalent about their age identity did not appear to identify themselves as old or young. Participants identifying as definitely old tended to use metaphors in line with the concept of masquerade and mask of ageing, however the authors argue that when considered within the framework of stigma this can be understood as attempts to resist the stigma associated with old age by distancing themselves from other old people. This study highlights the heterogeneity of identity in older age, supporting theories of the third age (Gilleard and Higgs 2002, 2005) and also provides empirical research critiquing the theory of masquerade (Biggs, 2005) and the mask of ageing (Featherstone, Hepworth et al. 1991) for not taking into account influences of ageism and stigma. Participants tended to underplay the impact of chronic conditions on their everyday lives and some emphasised their 'advanced' older age as vindication of their ill health.

This brings us to the next section examining in further detail the literature on chronic illness, self-identity and biography.

Chronic illness, self-identity and biography

The sudden onset of chronic illness is one example of what Giddens described as a 'critical situation' (1979: 123) that can be drastically disruptive to the structures of everyday life, leading to overwhelming and dominating uncertainties. Bury (1982) drew on this notion in his seminal work conceptualising chronic illness as biographical disruption which was based on a qualitative study of people aged under 64 years newly diagnosed with rheumatoid arthritis. Bury (1982) identified three aspects of disruption. First, the disruption of taken-for-granted assumptions and behaviours, which brings concerns about bodily states and decisions regarding seeking help to the forefront of consciousness. Second, the disruption of explanatory systems that require the rethinking of a person's biography in an attempt to repair the divisions between body, self and society. Third, there is the response to disruption that involves a mobilisation of material and cognitive resources available to people. For those who are dominated by the illness, access to medical knowledge becomes

particularly important as a way to separate the disease from the individual's self, legitimising illness and disability, and medical intervention. Other resources mobilised include supportive social networks and economic resources.

Bury's (1982) conceptualisation of biographical disruption has been highly influential, leading to many other sociological studies applying a biographical approach to people with a range of chronic conditions at different time points after onset or diagnosis. Some of these studies will be discussed later in this section.

Writing at a similar time to Bury (1982), Charmaz (1983, 1987) also argued that those who are suffering from a chronic illness often experience a loss of self. Rather than focusing on the narrative processes like Bury (1982), Charmaz (1983) discussed the ways in which illness threatens people's sense of self, drawing on a symbolic interactionist framework. Based on interviews with 57 people with a range of chronic illness, such as cardiovascular disease, diabetes and cancer (aged 20-86 years, with the largest proportion aged 40-60) Charmaz (1983) identified four sources of suffering loss of self, which develop from the conditions and content of experiencing chronic illness. These are; 'living a restricted life' that revolves around the illness and treatment regimens; 'social isolation' and shrinking social networks; 'discrediting definitions of self' that arise during explicitly or implicitly negative or embarrassing social interaction, devaluing a person's positive self-image; 'becoming a burden' as a result of physical dependency and the associated shifts in relationships with family and friends who act as carers. Focusing on the response to loss of self in later work, Charmaz (1987) argued that maintaining or recreating a valued identity becomes highly significant and failure to do so is often regarded as a failure of self. She referred to identity as 'attributes, actions, and appraisals of self' that also account for a person's 'aspirations and motivations for future identities' (1987: 284). She identified four identity levels that chronically ill people aim to achieve, either implicitly or explicitly, at different times during their illness. The identity levels are categorised according to their relative difficulty to attain and level of activity implied within them. Firstly the 'supernormal identity' involves people striving for extraordinary achievement in conventional worlds, participating more fully than others who were not chronically ill, despite limited functioning. Secondly a 'restored self' refers to people who wish to return to their former lives and expect to recreate previous identities before illness. Thirdly a 'contingent personal identity' is a hypothetically possible

identity but is uncertain because of illness, applied mainly to those who aimed for a 'supernormal identity' or a 'restored self' first but fail to realise it. Lastly, 'the salvaged self' refers to those who attempt to continue some favoured personal attribute or activity from the past or attempt to present themselves to others in a positive light despite the limitations of their illness. Charmaz (1983) argued that the experience of chronic illness becomes an arena where the Western values of independence, individual responsibility and hard work, rooted in the Protestant Ethic, are played out. Consequently dependency has very negative connotations and chronically ill people can feel they are a burden.

These findings relate to those of a seminal study on attitudes to health and illness of working class participants, aged 50-60, from a deprived area of East London (Cornwell 1984). A structure of moral belief was identified that related to the 'capitalist work ethic', the concept that hard work and discipline are duties that benefit both the individual and society. This ethic underpinned attitudes towards work and accounts of work which in turn informed participants' approach to health and illness. Even when a person was ill or retired it was important for them and others to 'establish their credentials as (previously) good workers and as people who have never not been willing to work' (Cornwell 1984: 71). Another study that focused on a similar cohort of participants, 30 years after Cornwell's (1984) original study, revealed a similar moral, hierarchical approach to illness despite the significant social and cultural changes that have taken place over the time period (Elias and Lowton 2014). Based on interviews with 15 participants aged 80-93 living in South East London, from mainly working class backgrounds the authors identified a moral framework for health problems. However within the context of advanced older age, participants demedicalised some health problems by attributing them to old age while upgrading some illnesses perceived to be more serious in older age. When they had experienced challenges to their moral health beliefs by health care professionals and services they expressed feelings of disempowerment but resisted readily adopting the 'sick role'. Instead they sought to maintain control over uncertain health and presented themselves as stoic, useful people.

The importance of moral and social frameworks in making sense of illness have been demonstrated by an interview study of people (aged 26-68) living with rheumatoid arthritis for five years or more (Williams 1984). Williams (1984) put forward the

concept of 'narrative reconstruction' to refer to the way in which people try to make sense of biographical disruption by attempting to repair the links between body, self and society to reconstruct a sense of order and purpose. This involves their attempts to understand the 'genesis' or cause of their illness in terms of past experiences and 'to affirm the impression that life has a course and the self has a purpose or *telos*' (1984: 179). Using detailed data from three case studies Williams (1984) illustrated the different ways in which people make sense of their illness by engaging moral, religious, political, sociological or historical factors to make narrative links between self and society, for example linking employment conditions with the onset of rheumatoid arthritis. The concept of narrative reconstruction is valuable in understanding responses to biographical disruption in the longer term and highlighting the link between the personal experiences of chronic illness and wider societal influences. However it is important to note that Williams (1984) did not focus on older people in developing his theory.

A key question raised by the concept of narrative reconstruction (Williams 1984) is how the nature and severity of the illness and participants' age and social context may influence how people respond to the disruption caused by chronic illness and attempt to make sense of these changes. There is some evidence that severity of stroke and lower expectations for recovery in older age have an important influence on illness narrative typologies, as demonstrated by (France, Hunt et al. 2013). This study analysed the narratives of 18 stroke survivors (aged 44-85), up to seven years after stroke using Frank's (1995) three types of illness narrative, namely; 'restitution' where illness is viewed as a temporary interruption and the person expects to fully recover, 'chaos' described as 'antinarratives' as the narrative is without temporal order and is characterised by despair, hopelessness and vulnerability, and 'quest' where the illness is accepted and seen as an opportunity or challenge, or as providing a sense of purpose. Frank (1995) defined three subtypes of quest narratives; 'quest memoir' which are stoical narratives that incorporate illness into life, 'quest manifesto' where special insights are gained from the illness experiences and this can be used to help others, 'quest automythology' which involves self-reinvention and individual transformation. Although the original aim of France et al. (2013) was to examine gender differences they found that severity of stroke and expectations for recovery had more influence on narrative genres than gender. The majority of participants (eight), who had experienced greater disability post stroke, presented 'quest memoir'

narratives, indicating acceptance and adaptation to the effects of stroke. They commonly referred to feeling lucky compared to other stroke survivors who were worse off, with some older participants indicating lower health expectations due to age. The interviews of three participants corresponded to chaos narratives, four to restitution narratives and one had no single dominant genre. No narratives corresponded to quest manifesto or quest automythology. Narratives of two male stroke survivors lacked narrative form which the authors link to the recency of their stroke as they had been interviewed within the first year post stroke. Participants were from a range of ages, raising the question of how these typologies apply to the narratives of older stroke survivors aged 75 and over.

Severity of stroke and older age have been shown to influence response to stroke (Becker 1993). An interview study of 216 stroke survivors (aged 50-105) found that stroke was experienced as a biographical disruption, made worse by higher levels of disability. However stroke survivors attempted to achieve biographical continuity to create a 'fit' with their limitations and resources by developing a series of strategies that involved enduring setbacks and lowering expectations, experienced as a greater challenge for those who had higher levels of disability. The importance of multiple morbidities, as well as age, in influencing the response to stroke has also been demonstrated by a study of 57 stroke survivors in the US (aged 46-88) interviewed at five intervals from 1 to 24 months post stroke (Faircloth et al., 2004). Multiple morbidities, older age and personal knowledge of stroke and knowledge provided through relationships with other stroke survivors allowed participants to minimise the biographical disruption of stroke and view stroke as part of their sense of self. Many participants had suffered other illness prior to their stroke and the stroke was often regarded as having far less of an impact than other health concerns, such as arthritis. The meaning of stroke was interpreted within the context of old age, normalising it as a natural part of the ageing process, therefore stroke was experienced as a continuity of identity or 'biographical flow'.

There is evidence that people with conditions other than stroke interpret their illness experience within the context of older age. The concept of 'biographical flow' (Faircloth et al., 2004) has also been applied to experience of older people (aged 73-94) with late stage chronic kidney disease (CKD) (Llewellyn, Low et al. 2014). Participants experienced initial diagnosis as a shock, however they normalised their

condition, regarding illness generally as the embodiment of old age and therefore a fate to be accepted. Participants reported not experiencing symptoms of CKD and therefore did not perceive it as a disruption, however all had co-morbidities including stroke and diabetes and the authors argue that symptoms of CKD, such as fatigue and pain, were lost among symptoms of other illnesses. Participants drew on discourses of natural ageing to construct narratives of 'biographical flow'. The importance of older age in the process of narrative reconstruction has also been demonstrated for people with osteoarthritis (Sanders et al., 2002). Participants (aged 51-91) experienced osteoarthritis as a biographical disruption in terms of the practical difficulties experienced, such as limited mobility, however the condition was also perceived as a normal part of their ongoing biography, constructed as part of their 'inheritance' and as a normal part of old age. Older age was an important resource in narrative reconstruction as participants drew on their identity as older people and on common cultural images of ageing, minimising their symptoms and presenting themselves as independent or 'successfully old', emphasising that they did not want to be a burden to society or their families.

Although the relevance of the nature and severity of illness, the context of older age and multiple morbidities have been demonstrated in the relation to stroke and other chronic conditions (France et al, 2013; Faircloth et al., 2004; Llewellyn et al., 2014; Sanders et al., 2002), the study participants were from a wide age range, including those in their 40s and 50s and the authors do not comment on how the experience of chronic illness may differ for this younger age group compared to those of more advanced older age.

There is evidence to suggest that those experiencing the onset of chronic illness at a young age respond differently to those experiencing onset of illness at an older age. Findings of two interview studies of people who experienced early onset of illness based on participants who were visually impaired (aged 30-45, mainly due to juvenile diabetes) and those who had lived with physical impairment for 30-66 years, (aged 56-72, mainly due to polio and multiple sclerosis) indicated that even in older age and despite previous hardships, illness was experienced as a recurring biographical disruption (Larsson and Jeppsson-Grassman, 2012). Further physical decline was experienced as more challenging to identity even though participants had lived with the condition for most of their lives. This study highlights the different meanings of

chronic illness for those experiencing early onset compared to participants in other studies who were older when they experienced the onset of stroke (Becker, 1993; Faircloth et al., 2004), CKD (Llewellyn et al., 2014) and osteoarthritis (Sanders et al., 2002), suggesting that lower health expectations in older age play a role, particularly when older people compare themselves to their peers.

The importance of age as well as the nature of the condition in influencing responses has been shown in a study of younger participants with ulcerative colitis who were cured by undergoing radical surgery which left them permanently faecally incontinent (Kelly, 1992). The nature of the radical surgery had a profound impact on physical appearance and functioning of the body which often 'swamped' all other aspects of self, implying that other conditions that have less of a visible impact on appearance, including less debilitating strokes, may have a less disruptive impact on the self. Although Kelly (1992) does not state the age of participants, ulcerative colitis is described as a condition that affects people in young adulthood 'in the prime of life', implying that the radical surgery was experienced as especially disruptive to identity due to the young age of participants. Returning to work and re-entering the world of intimate sexual relationships after the surgery were experienced as particularly challenging to participants' identity. This suggests that for those who are in advanced older age, who have retired and are perhaps less concerned with re-entering the world of intimate sexual relationships, chronic illness may have less of a profound impact on the self.

There is evidence that cancer has also been experienced as biographical disruption based on an interview study of participants (aged 26-77, mean 47.5 years) with different types of cancer (mostly breast or head and neck) interviewed at various stages (median of 18 months post diagnosis) (Mathieson and Stam 1995). Participants experienced a sense of stigma as a cancer patient, and experienced disruptions to relationships and plans for the future. They engaged in 'biographical work', incorporating cancer into revised biographical narratives through negotiating the meaning of cancer for the self within the context of ongoing social relationships. The level of biographical disruption experienced by these mainly middle aged participants with cancer (Mathieson and Stam, 1995) and younger participants who had undergone radical surgery to cure ulcerative colitis (Kelly, 1992) appear to be very different to the experiences of older participants in studies discussed above

showing that chronic illness was perceived as a normal part of ageing and therefore experienced as a 'biographical flow' (Faircloth et al; 2004; Llewellyn et al., 2014, Sanders et al. 2000). This indicates that response to illness is very likely to differ according to age.

In contrast to the experience of participants undergoing radical surgery to cure ulcerative colitis (Kelly, 1992) and those with cancer (Mathieson and Stam, 1995), the concept of biographical disruption has been found not to apply to the experience of people with elevated cholesterol (Felde 2011), demonstrating that the nature and the symptoms of the condition are also important factors in influencing responses. Participants (aged 42-80) were found not to have experienced elevated cholesterol as a disruption to identity due to a lack of symptoms and because medication regimens and dietary restrictions could be integrated into the patterns of their everyday life.

Previous experiences have been shown to have an important influence on the response to chronic illness and impact on biography. There is evidence that illness has been experienced as a 'biographical reinforcement' based on a study of haemophilic men and homosexual men who were HIV positive (Carricaburu and Pierret 1995). For haemophilic men who had organised their lives around their illness prior to their HIV diagnosis, this was experienced as a continuation of their biography as people living with a genetic condition. For the homosexual men the initial diagnosis was experienced as a biographical disruption but this led to a reworking of biographical narratives, reinforcing their identity as belonging to a generation of men who fought for the recognition of homosexuality. By reinterpreting their illness in relation to their individual and collective past experiences both groups of men attempted to give continuity to their biographies, referred to as biographical reinforcement. Previous experiences have also been found to mediate the impact of colorectal cancer on biography (Hubbard, Kidd et al. 2010). Based on a study of mainly male participants (aged 31-85 years) interviewed three times over the course of the first year after diagnosis, those who had experienced previous hardships were found to be less likely to experience colorectal cancer as a biographical disruption. Some participants experienced the condition as a threat to identity and for a few one way of coping with this disruption was to continue to work. However others experienced a disruption to their daily lives but not to their identity due to their 'hard

lives', which included previous experiences of a life-threatening illness and death of family members. These studies indicate the importance of taking into account the context of people's lives when examining response to chronic illness, particularly previous experiences of illness and family bereavement.

The significance of previous experiences in relation to response to stroke has been demonstrated in a case study of a 65 year old woman, interviewed on multiple occasions two to nine months post stroke (Kaufman 1988). The participant engaged in biographical work to make sense of the cause of her stroke within the context of her life and the hardships she had endured through caring for two of her three sons, suffering from physical and mental illness. Drawing on her maternal role and a moral framework based on previous hardships, she constructed a narrative to accommodate the stroke within her biography. Previous hardships have also been found to influence the experience of stroke, together with older age. Based on a sample of working class stroke survivors (aged 40-87 years) living in the East End of London, interviewed 10 months post stroke, responses to stroke were found to be heavily influenced by the context of participant's lives, particularly old age (Pound et al, 1998). Although the majority reported problems experienced as a result of the stroke, they sought to minimise the impact of the stroke during the interviews. Many had experienced 'hard lives', including war, poverty, and previous ill health, and so they had already had to adapt to changing circumstances and mobilise resources available to them, such as social support. Expectations of health were shown to decrease in old age and stroke was viewed as a natural part of the ageing process. Therefore due to their age and possibly their social class position participants were familiar with the worlds of pain, suffering and death (Bury, 1982) and so their stroke was not perceived as an extraordinary event. Rather than engaging in narrative reconstruction after biographical disruption the participants were found to have experienced the stroke as a 'normal crisis'. However the sample were from a range of ages, raising the question of how far the concept of 'normal crisis' can be applied specifically to stroke survivors of advanced older age, aged 75 and over.

There have been a number of other qualitative interview studies on the experience of stroke and adjustment and coping after stroke which have identified the impact on identity, such as Dowswell, Lawler et al. 2000, Clarke and Black 2005, Carlsson, Möller et al. 2009, Eilertsen, Kirkevold et al. 2010, Erikson, Park et al. 2010, de

Guzman, Tan et al. 2012). However findings were not developed within a broader theoretical framework.

A review of qualitative studies on adjusting after stroke draws parallels with the concept of resilience, however studies on the experience of stroke have not specifically examined the concept of resilience (Sarre et al., 2014). Although it is a contested concept, resilience has been conceptualised as a process by which people bounce back from adversity, such as ill health, and reintegrate and grow from the experience (Resnick 2014). Sarre et al. (2014) suggest that stroke can have a profound effect on stroke survivors' sense of self and on their relationships. The authors identify the importance of narrative reconstruction as a resilience practice and point out that the interview process is helpful in this respect. Some of the studies reviewed also found that downward social comparisons (comparisons to other worse-off stroke survivors or various other imagined alternatives) were important in adjusting after stroke which the authors argue is not something noted in resilience literature.

There is a growing literature focusing on resilience in older age. This includes a study of 139 people (aged 70-80) that found that maintaining a sense of self-identity through the process of narrative reconstruction was an essential strategy in developing resilience in relation to experiences of adversity, including ill health, death of a relative and caring for a disabled or ill relative (Hildon, Smith et al. 2008). Findings showed that participants with resilient outcomes gained a sense of continuity from relying on the same ways of handling adversity over time and by contextualising adversity in terms of past events, supporting other studies showing that past experiences mediate the impact of chronic illness (Carricaburu and Pierret 1995). However the authors acknowledge that the sample was mostly affluent and educated and that findings may differ for a more diverse sample including participants from economically disadvantaged backgrounds.

Summary

Over the twentieth century older age has been socially constructed as a period of economic and social dependency linked to the imposition of earlier retirement, the legitimisation of low rates of state pension, residential institutions for older people that

serve as a means of social control and community care services aimed at 'passive' older people (Townsend, 1981). Profound changes in the nature of ageing since the 1950s associated with the breakup of traditional institutions such as retirement and the welfare state, have contributed to what has been regarded as a crisis in the social and personal identity of older people due to marginalisation and insecurity in a capitalist society (Phillipson, 1998). However since the 1980s the experience of old age has become increasingly heterogeneous with distinctions made between the third age associated with a period of active and fulfilling retirement brought about by improved health in older age and an increase in earnings and private pensions, and the fourth age associated with frailty, ill health and financial hardship (Laslett, 1989). However there are very few studies on identity in older age, which are essential for an understanding of how older people living in modern Britain construct and understand their identity.

There are many studies that have taken a biographical approach in understanding the experience of participants with various chronic conditions. Findings have shown the importance of taking context into account with responses to chronic illness differing according to the nature and severity of the chronic condition, age of participants and their previous experiences and hardships, including other chronic conditions, poverty and bereavement. Evidence suggests that after initially experiencing illness as a biographical disruption (Bury, 1982), some people engage in narrative reconstruction as an attempt to repair this initial disruption, making sense of the illness by incorporating it into their biography (Williams, 1984), with older age identified as an important resource in this process (Sanders et al, 2002; Faircloth et al 2004). However there is evidence that some stroke survivors have not experienced stroke as a biographical disruption, rather it has been experienced as a 'normal crisis' (Pound et al., 1998) due to mediating factors associated with old age, including lower health expectations and previous experience of other chronic illness and hardship such as war and poverty.

However these studies mainly focus on participants in mid-life, with calls for more research to be carried out on older age groups (Williams, 2000). The population is ageing with more people living into advanced older age and experiencing chronic illness, including stroke, which is one of the leading causes of adult disability in England (Stroke Association, 2016). The prevalence of stroke is increasing due to

higher numbers of stroke patients surviving, with stroke causing a greater range of disability than any other condition (Adamson et al., 2004). Therefore stroke is a condition that is significant for sociological studies into the experiences of chronic illness for older people and the impact on identity. However no studies focusing specifically on identity among older stroke survivors from a biographical approach have been identified within the last 18 years, during which time there have been significant changes to stroke care (National Audit Office 2010). This indicates a clear gap in our understanding of self-identity among people of advanced older age following a stroke, and more specifically on whether stroke is experienced as a biographical disruption in advanced older age and how older stroke survivors may engage in the process of narrative reconstruction. Understanding the ways in which older people experience and interpret stroke and how circumstances may differ for those in advanced older age compared to those who are younger is essential to address this gap in the theoretical literature. This will inform the design and delivery of health and social care services to ensure that older stroke survivors' are able to access services appropriate to their needs and circumstances.

All of the studies discussed in this chapter are predominantly based on interviews with individuals. However I argue that this approach overlooks the impact of chronic illness on spouses and partners, who often assume the role of carer. It is important to consider the meanings and disruptions of chronic illness both for the patient and their partner. Broadening this individualistic perspective, I now focus on the literature on couples' experience of and response to chronic illness and the impact on couple identity.

Chapter 2: Literature Review: Self-presentation, Interaction and Language

Introduction

As discussed in Chapter One Goffman (1959) takes the perspective that identity is socially produced. From a symbolic interactionist perspective, he argues that the 'self' is created in relation to social interaction and the meaning attached to particular actions in everyday life. Symbolic interactionists emphasise the importance of empirical research, with a focus on qualitative methods, into how people create meaning during social interaction in everyday life and how they present and construct self-identity and how they define situations in relation to others.

From a symbolic interactionist perspective Goffman (1959) explores meaning in language and interaction in everyday life and the construction of identity through the presentation of self and impression management. As discussed in Chapter One he develops the concept of 'front', referring to the way in which people present themselves to others during social interactions or 'performances', with both verbal and body language being an important part of performances. Goffman (1959) argues that individuals aim to construct an idealised front that fits with society's norms and laws, legitimating their social role. He views the creation of the self as being achieved through social interaction, with language central to this process. However he also acknowledges the significance of the body in the creation of self, arguing that the body is fashioned, manipulated and presented according to social and cultural practices and rituals. Meaning is given to the body through social interactions and performances.

Following on from Goffman's approach to self-presentation and interaction, this chapter considers two different approaches to examining self-presentation and interaction in relation to illness narratives. First, studies examining the interaction and the co-construction of narratives between two participants in joint interviews are discussed as it is important to consider the meanings and disruptions of chronic illness both for the patient and their partner. Second, studies examining the use of language in interaction from a sociolinguistic perspective are discussed. The final section brings together a summary of the research findings and highlights relevant

gaps in our understanding of the co-construction of chronic illness narratives, leading to the section presenting the overall aim and research questions.

Co-construction of chronic illness narratives

As discussed in Chapter One, it is now well recognised that chronic illness can lead to a fundamental re-thinking of a person's identity and biography, can affect relationships and material and practical affairs, and may lead to the need to restructure future goals and priorities (Bury, 1982). The conceptual strategies that people employ in the aftermath of biographical discontinuity to create a sense of coherence, stability and order were described by Williams (1984) as 'narrative reconstruction', which involves narrativising chronic illness within the framework of one's own life history. As discussed, studies have shown the significance of an individual's whole biography for the meanings they assign to chronic illness and processes of narrative reconstruction. Support provided by social networks is also identified as a contextual factor and resource that is often critical to the ways in which illness is lived and negotiated in people's lives. The important role played by spouses has been identified in relation to the process of identity reconstruction by people with various chronic illnesses, including stroke, based on joint interviews with 60 couples (Corbin and Strauss 1987). People with chronic illness engaged in 'biographical accommodation' as a way of managing the illness through actions that aimed to achieve a sense of control and continuity, for example through testing the limitations of the body and attaching new salience to old activities as well as carrying out new activities. Spouses often acted as 'identity validators', helping the ill person to achieve a sense of 'identity reintegration', with this often involving denying or minimising their failed everyday performances, for example relating to personal care.

The majority of studies that consider the experience of chronic illness for other members of the patients' social network have focused on the demands of providing ongoing care to a person who is chronically ill, for example, Scholte op Reimer, De Haan et al. (1998), Clarke and Smith (1999), or how the experience of chronic illness of a family member affects the lifecourse of those around them, for example, Ohman and Soderberg (2004). A meta-ethnographic review of seven studies on informal carers of stroke survivors (mostly spouses, with an average age of 55-65 years)

mainly interviewed within 12 months post stroke concluded that their experience was one of biographical disruption, drawing parallels with the literature taking a biographical perspective on the experience of chronic illness (Greenwood and Mackenzie 2010). The studies indicated that carers experienced both loss and change in roles and relationships and in their sense of identity, although there was less marked biographical disruption for older carers and those who were already carers due to lower expectations or fewer conflicting demands, such as paid employment (Greenwood and Mackenzie, 2010). However these studies on the experience of caring were based on individual interviews, as were the majority of studies on the experience of chronic illness, reinforcing an individual perspective rather than focusing on the experience of chronic illness for both patients and spouses together. Relying only on the individual interview, as Lawton (2002) notes in the context of qualitative work, may lead to particular types of narratives that tend to give less emphasis to the 'mundane', daily aspects of 'coping with' the diseased body, despite physical aspects forming a prime focus of the experience of chronic illness. Lawton therefore called for a shift from the dominance of the single research interview and 'opening the door to a broader range of methods and methodologies to give access to a more broad-ranging and comprehensive picture of individual illness' (2013: 35).

Joint interviews (in addition to individual interviews) with participants (aged 25 and over, with the majority aged 55 and over) from families where one member was diagnosed with coronary heart disease or coeliac disease revealed that an important way of adjusting to life after the onset of chronic illness was through maintaining a sense of stability by continuing normal family life and relying on family identities (Gregory 2005). Interviews focused on how families managed dietary recommendations during their everyday lives. The 'natural' gendered division of domestic tasks reinforced the sense of 'being a family', however for some families the onset of chronic illness and retirement meant that these roles became more flexible than they had been in the past. Participants found ways of constructing the dietary demands as normal within the family relationships, representing an on-going process of maintaining continuity whilst accommodating change. The routine and repeated family practices associated with the notion of the family as natural and gendered caring as natural, offered ontological security to people with chronic illness and their families (Gregory 2005). This study is one of the few studies on chronic illness that

explicitly draws on Giddens (1991) theory and highlights the significance of the family context in the experience of chronic illness. However she does not explore the nature of the joint interview data in comparison with the individual interviews, commenting only that 'this was, in fact, advantageous in that a dialogue between members of each couple often revealed interesting nuances in their views' (2005: 377). This highlights the need for further research on how couples interact and engage in the construction of joint chronic illness narratives.

I argue that the disruptions to identity caused by chronic illness need to be considered together for both the patient and their spouse, rather than only for each party individually. An important way forward, as Gregory (2005) has shown, is therefore to conduct joint interviews with the chronically ill person and their partner, and to focus not only on *what* is said in terms of the content of talk but also to analyse the style of the narrative, in terms of *how* people talk about and present events. A few studies have employed joint interviews in examining experiences and responses to chronic illness but have mainly only presented the content of joint accounts. This includes a study of male coronary patients and their wives, aged 30-70 years, which described how the marital relationship influenced men's styles of adjustment, identifying two main styles (Radley 1989). The 'active-denial' style where the illness was regarded as a threat to men's identity as breadwinner and couples would strive to achieve the same roles and activities as they had done before the illness, was more common among couples with segregated gender roles. This contrasted with the 'accommodation' style of adjustment where couples accepted the illness and modified their lifestyles accordingly, which was common among couples with shared conjugal roles. Another study compared adjustment to prostate cancer among couples aged 50-64 years (late middle age), 65-74 years (young-old) and 75-84 years (old-old) (Harden, Northouse et al. 2006). Couples in the oldest group reported slower recovery from illness than the younger couples but late middle aged couples reported greater disappointment at their inability to reach life goals and establish financial security. This suggests that age has an important influence on the impact of chronic illness on couples' experiences and couples' identity, supporting findings presented in Chapter One that age mediates that experience of chronic illness (Sanders et al, 2002; Faircloth et al 2004; Pound et al, 1998). A study exploring couples' reactions to one partners' diagnosis of dementia also used joint interviews and presented a model describing the oscillating process couples go through in making sense of the

experience of early stage dementia and adjusting to losses (Robinson, Clare et al. 2005). Although the authors did not examine interaction between couples, they suggest that this is an important focus for further research to gain a better understanding of the ways in which couples engage in the construction of joint narratives to examine the impact of chronic illness on identity.

A small number of studies based on joint interviews with couples have focused on interaction and language as well as the content of interviews as a method to examine the experience of chronic illness in relation to narrative and identity, and it is these which will now be discussed. Based on multiple joint interviews with one married couple, a case study examined the process of meaning construction by the couple to gain insight into their joint interpretations of their 'marital reality' and shared social world (Gerhardt 1991). Through detailed analysis of three different 'stories' told by a couple prior to the husband's coronary artery bypass surgery, the couple are shown to strive together to present a 'unified front', creating an image of their relationship as competent and 'normal', despite experiencing chronic illness and financial hardship. Moreover through their 'story' about the low rate of sickness benefit, they presented themselves as an honest working couple abandoned by an uncaring welfare state, thus legitimating their identity as a respectable couple.

A subsequent joint interview study illustrates the value of focusing on language and interaction between strokes survivors and their spouses, drawing on Conversation Analysis (Manzo et al. 1995). Joint interviews were carried out with 14 male stroke survivors (including one with aphasia) and their wives, and 'control' interviews with men who had various other chronic conditions (e.g. arthritis) and their wives. In contrast to the presentation of a 'unified front' (Gerhardt 1991), the wives tended to dominate, for example, by answering questions directed at their husbands and engaging in 'competitive' storytelling, supplementing, correcting and contradicting their husbands' stories. Control patients' wives generally withheld their participation until they were explicitly invited to speak whereas the stroke patients' wives often initiated their speech without explicit invitation. It was argued that stroke survivors' lacked agency in the narratives and that the conversation dominance were 'not 'gender' effects but were practices through which any person can be infantilised through conversation' (Manzo et al. 1995: 324). However as female stroke survivors were not included in the sample this raises the question of whether these interactional

patterns would emerge in joint interviews with female stroke survivors and their husbands.

Carers were also found to dominate the conversation in a joint interview study focusing on patterns of interaction between informal carers and people with dementia (Shakespeare 1993), as found by Manzo et al. (1995). Shakespeare (1993) draws on Goffman's work (1963) as a framework to interpret the findings, arguing that rather than intending to disempower the person with dementia, carers were managing a 'spoiled performance'. Carers distanced themselves from the situation by almost ignoring the person with dementia but also promoting the patient's competence by 'stealing' the scene to construct the conversation as 'normal'. Shakespeare (1993) argues that social conventions meant the rules of 'normal' conversation were conformed to and this became more important than the status of the participants, resulting in a performance that 'subsumes the players' (1993: 104). This raises the question of whether these patterns would apply to interaction between stroke survivors and their spouses, particularly those with aphasia who may engage in interaction that does not always conform to the social conventions of 'normal' conversation.

A joint interview study of people with cancer and their informal carers examined the needs of carers based on analysis of narrative styles as well as narrative content (Morris 2001). Based on 38 joint interviews and 41 individual interviews with people with cancer (aged 26-83) and their informal carers (aged 20-76), the majority of whom were spouses, three narrative styles were identified; 'I and I' referred to couples who took turns to present 'semi-monologues'; 'working it out together' referred to couples who talked between themselves to negotiate a joint response; 'we' referred to couples who constructed a shared narrative presenting a united stance as morally competent actors jointly managing the illness. However discussion of these styles is limited and it is not clear how the narrative styles were identified during the analysis. I argue that a further understanding is needed of the different ways in which couples construct narratives together to engage in the presentation of particular identities in relation to the experience of chronic illness.

Similar to the 'we' narrative style identified by Morris (2001), couples were found to display a sense of 'we-ness' in a recent study also focusing on both content and style

of narrative based on joint interviews with older couples (aged 60 years and over) where both were living with disabilities (Torgé 2013). In a study examining experiences of spousal care, the 'we-ness' style displayed couples' shared experiences, common history and interdependence on each other for help with everyday tasks, involving frequent use of 'us' and 'we', confirming each other's points and finishing each other's sentences. Torgé (2013) argues that interviews are a method where couples are 'on-stage', giving an example of a couple where a husband had slurred speech and the wife acted as an 'interpreter', engaging in a 'balancing act' allowing the husband to have independence but with the wife providing help when necessary, reflecting the help-giving that occurred in the couple's everyday life. Some disagreements between couples were identified, for example one couple disagreed over whose illness was worse, reflecting that, despite couples generally presenting themselves as a unit, both spouses had different experiences of disability that they needed to communicate in order to support each other. However aspects of conflict and spousal burden could be underplayed in joint interviews and asking couples about mutual care and support during the interviews is likely to encourage narratives of 'we-ness' (Torgé, 2013). This study raises the question of how applicable these findings would be to joint interviews with older stroke survivors and their spouses and the extent to which couples may engage in a 'we-ness' narrative style or display disagreements, particularly where spouses are also living with chronic conditions and both partners may be interdependent on each other. Torgé's (2013) example of the couple who displayed a 'balancing act' may be particularly relevant for stroke survivors with aphasia.

Couples were found to negotiate and coordinate their narratives, filling in gaps and prompting each other in another study based on multiple joint interviews with six couples in long-standing relationships (30 years or more) where one partner had motor neuron disease (Sakellariou, Boniface et al. 2013), supporting the collaborative narrative styles identified in other joint interview studies discussed (Morris 2001; Torgé 2013). This raises the question of how far these collaborative styles of narrative would apply to interaction between older stroke survivors and their spouse. Some participants with motor neurone disease had communication problems and partners would often expand on short answers given by the person with motor neuron disease, who would then signal approval or disapproval of the expanded narrative. Joint interviews are valuable in understanding how couples co-construct shared

meaning and experiences, and participating in a joint interview offers the opportunity for those with communication problems to participate in research (Sakellariou, Boniface et al. 2013), which is likely to be a methodological advantage applying to stroke survivors with communication problems.

The collaborative narrative styles identified in joint interview studies (Sakellariou, Boniface et al. 2013; Torge 2013; and Morris 2001), as discussed, were also identified in joint interview data with cohabiting couples on the topics of work and childcare (Bjornholt and Farstad 2012) indicating that this narrative style also applies to younger couples of working age with young children, on topics other than chronic illness and disability. Drawing on three different studies, findings focusing on patterns of interaction demonstrated that some couples engaged together in joint reflection, corroborating each other and encouraging one another to share information and stories. Couples provided support for each other's presentation of identity, for example one husband presented himself as having good domestic skills, which was supported by his wife who said they shared the household chores equally. Couples would sometimes discuss topics amongst themselves, reflecting 'back stage' behaviour (Goffman, 1959), placing the interviewer in an observer role. However some couples challenged each other and engaged in debate and conflict about particular issues, some of which appeared not to have been previously spoken about, providing further insight into couples' views and attitudes, which would have been difficult to obtain through individual interviews (Bjornholt and Farstad 2012). For example, one couple disagreed over their child's structured eating and sleeping routine and another couple displayed conflict when the husband expressed that he felt it was unfair that his wife was paid twice as much as him.

Joint interviews are an ideal method to observe 'family display' (Bjornholt and Farstad, 2014), referring to 'the process by which individuals and groups of individuals convey to each other and to relevant audiences that certain actions constitute "doing family things" and thereby confirm that these relationships are "family" relationships' (Finch, 2007:67). The concept of 'family display' (Finch 2007) emphasises the social nature of family practices, where the meaning of a person's actions has to be both conveyed to and understood by others so as to be effective as constituting family practices. Finch (2007) argues that the need for families to be 'displayed' is increasingly relevant in a society where families and relationships are becoming more

diverse and fluctuate over time. Drawing on Giddens (1991) amongst others, she argues that intimate family relationships are of fundamental importance to a person's sense of identity in a changing social world. Relationships need to be displayed to have social reality and displaying family relationships are rooted in direct social interaction between participants and reinforced by a sense that others are supporting the social meaning established. Finch (2007) acknowledges that the concept of display draws on a social interactionist framework and there are similarities between the concept of display and Goffman's (1969) notion of performance, although it specifically relates to the family rather than an individual's identity. I argue that joint interviews are also an ideal method to observe the 'display' or 'performance' that couples engage in, to examine the construction of couple identity. Joint interviews are a 'space in which co-production of a public narrative is directly performed' (Polak and Green, 2015: 9), enabling the performative aspects of couplehood to be observed (Torge, 2013).

Focusing on the interaction between couples in analysis, referred to as a 'dyadic approach' is essential for understanding how, and whose, stories get told about chronic illness and for understanding the effects of biographical disruptions caused by chronic illness on the partner as well as the patient, and the relationship between them (Polak and Green 2015). In a study of how people make decisions about taking statins participants were given the choice of whether to be interviewed together or separately (Polak and Green 2015). Couples choosing a joint interview may provide data in itself as this possibly implies that these couples are more likely to engage in a collaborative narrative (Polak and Green 2015). Findings indicated that the couples participating in joint interviews engaged in shared performances and frequently displayed 'we-talk', as identified in other joint interview studies discussed (Bjornholtand and Farstad 2014; Sakellariou, Boniface et al. 2013; Torge 2013; and Morris 2001). However contradictions between couples were also evident. Three types of couple interaction were identified; 'Confirmatory accounts' were shared performances where couples echoed each other, reflecting their 'long-established shared way of describing the world' (Polak and Green, 2015: 8); 'Complementary accounts' were narratives where couples built on and strengthened each other's accounts; 'Contradictory accounts' were narratives where couples challenged and contradicted each other, engaging in negotiation of a shared narrative. These three types of couple interaction raise the question of how applicable they may be to joint

interviews with older stroke survivors and their spouses, however it is not clear how the three types of interaction were identified during analysis.

Work to date emphasises the performative aspect of joint interviews with couples and the value of focusing on the nature of interaction between couples in joint interviews. However, details of analytic approaches used are rare with published work not appearing to have taken a systematic approach to the analysis of interaction and narrative construction between couples. Based on a study of 344 black and white newlywed couples focusing on the 'story of their relationship', Veroff, et al. (1993) developed a systematic coding scheme for analysing interaction between couples in joint interviews. This involved coding each shift in speaker as one of six types of interaction, of which the first three types of interaction were categorised as collaborative styles of narratives and the last three as (explicit or implicit) conflictual styles. The code 'collaboration' referred to extending the idea of the spouse, questioning for information, answering questions that further the story or continuing a storyline that the spouse had previously begun. 'Confirmation' referred to a statement of agreement e.g. 'yes' or 'um-hmm'. Confirmation-collaboration referred to an interruption that affirms the previous statement of the spouse and then adds new material. 'Conflict' referred to disagreeing or interrupting the spouse with a negative response. 'Non-response' referred to explicitly avoiding responding to the spouse's previous comment. The code 'continuation' referred to continuing the narrative without reflecting on the previous comment from the spouse. Veroff et al (1993) present a systematic, practical method of analysis for joint interview data that ensures transparency, rigour and validity (Atkinson 1997).

A very recent study that is one of the few to draw on Veroff et al.'s (1993) coding scheme, focuses on the experiences of (non)retirement amongst farming fathers and sons in the UK focusing (Riley 2014). Joint interviews were carried out with 15 pairs of fathers (aged 65 years and over) and their sons from UK farms, in addition to individual interviews with each participant. A high degree of collaboration between fathers and sons was identified. Both participants would emphasise the advantages of the fathers' continued presence on the farm and participants would often use 'we', presenting the farm work as a team effort, despite the fathers generally lessening their work load as they had aged, illustrating a continual process of de-individualising the narrative. The continual turn-taking between father and sons provided an

opportunity for further 'intra-interview reflection' as participants continually layered and developed their joint narratives by posing questions to one another in a process of 'mutually choreographed agreement' (Riley 2014: 242). The process of 'revelation-through-collaboration' was identified whereby one participant would encourage the other to tell particular stories as part of 'scene-setting', which served as a narrative device for a participant to reaffirm the points they have made and also magnify the significance of points they will go on to make (Riley 2014). A process of 'story arching' is also identified which allowed fathers to contribute and lay claim to the narrative to ensure that they could present a particular identity within the interview. Both father and son worked together to produce a narrative that subtly cast the father in an active role, emphasising past contributions to the family farm, linking them to the present. However it is important to note that the health of participants is likely to be an important factor in terms of the nature of interaction as none of the participants were reported as being in poor health which could mean narratives were more likely to be collaborative. Also the type of relationship and possible implicit hierarchy between father and son may mean participants are more likely to engage in collaborative narratives. Riley (2014) acknowledges that family farming has been found to be very patriarchal in structure generally. This points towards the importance of the nature of the relationship between participants in joint interviews and how this can affect the power dynamics and nature of interaction.

Language use in interaction

Another approach to examining self-presentation is to focus on the use of language in interaction. Language and social interaction in everyday life are perceived by Goffman (1959) and symbolic interactionists more generally, as essential parts of the construction of self-identity. This notion has been influential in the sociolinguistic approach to the study of language in everyday life concerned with the social and cultural aspects and functions of language. Many sociolinguistic studies within a feminist framework have focused on gender and the next section provides an overview of these studies in relation to everyday interaction.

Gender and language

Sociolinguists have been increasingly interested in the performance of gender in everyday interaction, arguing that gender identities in society are reflected in the everyday use of language but also that everyday language influences the way in which gender identities are constructed. Studies indicate clear gender differences in the ways in which men and women communicate, based on everyday conversations in 'natural' settings rather than research interviews. An overview of the sociolinguistic literature found that despite the widespread belief in society that women talk more than men, evidence showed that in various mixed sex settings men talk more than women and talk for longer periods (Coates 2004). For example one study based on workplace conversations between colleagues of differing status showed that male managers spent more time talking or 'holding the floor' than subordinates but female managers did not, indicating that 'holding the floor' was associated with gender more than occupational status (Woods 1989). The myth that women talk more has been explained in terms of differing expectations of male and female speakers, meaning that when women talk at any length this is perceived as talkativeness (Spender 1980)

Men have also been shown to display more 'non-cooperative' language patterns (Coates, 2004). For example, a study based conversations between two different participants in a public setting (eg. a coffee shop) found that women used more minimal response words, such as 'yeah' and 'mhm', to indicate support for the other speaker and to facilitate conversations (West and Zimmerman, 1975). However men

were more likely to delay using minimal responses indicating a lack of interest and support for the speaker's topic, and men interrupted and overlapped more in conversation. Overlaps are instances of slight over-anticipation by the next speaker whereas interruptions prevent the other speaker from finishing his or her turn. In support of these findings a study of doctor-patient interaction also found that male doctors were more likely to interrupt patients but female doctors were less likely to, with male patients also more likely to interrupt female doctors (West 1998). Examples of other 'non-cooperative' strategies shown to be used more frequently by men include 'no response' or 'delayed response'. A study based on recorded conversations between seven married couples at home over a week or more and additional interviews with each of the participants separately to comment on extracts of their conversations found that women work harder to keep the conversation going but were less successful at achieving this (DeFrancisco 1998). Although women talked more and introduced more topics, men actually displayed more control over the interactions using 'no response' or 'delayed response'.

With regards to age, a review of studies of people of working age in the work place and public places examined the linguistic strategies used by male speakers to dominate female speakers, and reviewed studies of children examining the development of gender-appropriate language (Coates, 2004). However all of these studies have focused on healthy people of working age and children in everyday situations but do not examine identity construction through language use in relation to ill health and older age. I now discuss the limited studies of gender and language use in relation to the experience of illness.

The experience of illness, gender and language

The process of narrative reconstruction of the self (Williams, 1984) that occurs after biographical disruption caused by chronic illness (Bury, 1982) can provide important insights into how gender identities are performed and contested. One novel approach to exploring narrative reconstruction through language after illness is the comparative keyword analysis method based on a sociolinguistic perspective. Focusing on the experience of cancer a method has been developed to compare gender differences in language use in interviews and online cancer support groups (Seale, Ziebland et

al. 2006). Comparative keyword analysis is an inductive approach using computer software to compare bodies of spoken text, in this case by men and women, to identify differences in the frequency and type of words spoken. Based on this quantitative data, qualitative analysis is then carried out to analyse the context and meaning of the word clusters associated with the keywords. In interviews with 45 women with breast cancer and 52 men with prostate cancer significant gender differences were identified. Women used a greater number of 'people' words (eg. 'husband', 'her') and words referring to relatives (eg. 'mum', 'sister') as well as more personal pronouns referring to themselves (eg. 'I', 'me'). Comparative keyword analysis revealed that women were more likely to use the internet to seek social and emotional support and men were more likely to use the internet to seek information. Analysis of online postings by 900 women with cancer on a breast cancer forum and 153 men with cancer on a prostate cancer forum were also conducted. Findings showed that women focused more on the exchange of superlatives, such as 'lovely', 'amazing', 'wonderful', and words referring to feelings, indicating greater emotional expressivity supporting previous findings of the nature of women's interactional style (Boneva and Kraut 2002). In contrast men's use of language in online groups reflected their need to gather information. Findings demonstrate the continuing relevance of gender as a key variable in understanding experience of and response to chronic illness (Seale, Ziebland et al. 2006). However the importance of age as a key variable has been overlooked in this study, and the age of the interviewees or the members of the online forums was not stated.

Following on from this study, the same method of comparative keyword analysis was used to investigate the ways in which the biographical disruption of illness may be reflected in men's language use and performances of masculine identity (Charteris-Black and Seale 2009), within the context of much evidence indicating men's reluctance to seek help from health professionals and their reliance on female partners in health matters. Interview data from 99 pairs of male and female participants who had experienced various illness conditions, matched according to age (range 16-87 years, mean 49 years), socio-economic status, type of illness and gender of the interviewer was analysed. Younger men from higher socio-economic groups were found to express emotion using more direct styles such as swearing whereas middle aged and older men use more indirect distancing strategies such as metaphor use and generalisation, seeking to externalise illness experience as a

problem. However middle aged and older men appeared to resist dominant masculine norms by employing a more self-conscious 'feminine' language of feelings enabling them to construct new identities, associated with self-knowledge and emotional understanding (Charteris-Black and Seale 2009). However the study did not focus on older age with only ten participants aged 75 and over.

There are few sociolinguistic studies on men and women in old age, with studies mainly focusing on the effects of gender and age separately. One study that attempts to address this gap used comparative keyword analysis to examine the relationships between age, gender and language performance in 102 individual interviews on the experience of cancer with people diagnosed with different types of cancer (breast, prostate, ovarian, testicular, cervical, brain tumour, leukaemia and other childhood cancers) (Seale, Charteris-Black et al. 2008). Interviews were matched according to gender (men, women) and age group ('young' aged 16-28 years, 'mid' aged 40-55 and 'old' aged 65-83) to form six subgroups. Findings indicated that across all age groups women spoke a greater number of words than men, and older men spoke the least and young women spoke the most. Older men with cancer displayed a greater interest and social confidence in interacting with medical experts than women or younger men, approaching their illness as a 'problem' to be solved in line with patterns of 'hegemonic masculinity' and 'expert patient' identity. Older women demonstrated a greater emphasis on relationships and the maintenance of social support networks and the direct expression of emotion compared to men, supporting findings from their previous study (Seale, Ziebland et al. 2006). This study is important in understanding the different ways in which men and women approach illness through their narratives and the different resources they draw on in coping with illness, in relation to age. However Seale and Charteris-Black (2008) acknowledged that their sample of 'old' participants with cancer may not include older people who are frail and vulnerable, and therefore more marginalised. No other sociolinguistic studies on gender and old age have been identified indicating a significant gap in the literature.

The studies discussed in this section have all been based on the conventional method of interviews with individual participants. However joint interviews with two participants (for example, husband and wife, patient and informal carer) have been shown to produce new forms of data demonstrating the way in which narratives are co-constructed, reflecting the shared experience of illness and how the marital

relationship can mediate the experience and its impact on identity (Sakellariou, Boniface and Brown, 2013).

In one of a small number of studies discussing a comparison of individual and joint interviews in a health context, Morris (2001), as discussed, carried out a study on the needs of informal carers of men and women with cancer based on joint and individual interviews with patients and their informal carers, mainly spouses. She found that in individual interviews, patients and carers often produced very similar accounts that used identical phrases. In the joint interviews patients and informal carers roughly spoke equal numbers of words after an initial phase of the patient (regardless of gender) narrating their story, except where the patient was in poor health. However findings are not discussed in relation to gender and age groups or the relationship between the joint interviewees (eg. spouse, daughter, son) and the ways in which these contextual factors may affect the narratives produced. She argues that joint interviews offer a valuable method, particularly in relation to research questions that focus on a socially defined relationship. This suggests that examining differences in the language use of informal carers and the person with chronic illness, in addition to gender, may contribute to an understanding of the different ways in which chronic illness impacts on the identities of these two groups within a socially defined relationship.

While there are a small number of papers discussing the methodological merits and pitfalls of individual versus joint interviews, very few studies have carried out a systematic comparison of the two methods. Addressing this gap, one study examined the relationship between gender and interview context based on a systematic comparison of 58 interviews with individual participants and 37 mixed sex joint interviews on the same health related topics (the experience of pregnancy, parenting, and illness such as cancer and hypertension) (Seale and Charteris-Black 2008) The method involved matching mixed sex joint interviews with individual interviews with a female participant and individual interviews with a male participant, on the same topic and usually involving the same interviewer. Where possible the interviews were matched based on age of respondent and socio-economic classification. The number of words spoken by each participant was calculated and comparative keyword analysis was conducted to examine differences in relation to gender and interview context (individual, joint). Women spoke a greater amount of words and took more

turns to speak in both individual and joint interviews but women spoke significantly more and more often in joint interviews. This contrasts with earlier findings, as summarised by Coates (2004). However the authors acknowledge that the topics of health and illness are traditionally regarded as topics where women's experiences predominate. In individual interviews women used more singular pronouns (eg. I, me, my) indicating more talk about their personal experiences and in joint interviews women used significantly more plural pronouns (we, our, us), indicating more talk about shared experiences. However men were more likely to talk about shared experiences in individual interviews. In joint interviews women were less likely to talk about feelings (eg. frightened, confused, cope) but men were more likely to. Women referred more to wider social networks (eg. friends, neighbours) than men in individual interviews but joint interviews appeared to increase men's talk about social networks. Therefore joint interviews lead to a reduction in 'traditional' gender differences compared to individual interviews (Seale and Charitis Black 2008). However the relationship of the participants in the joint interviews and the influence this may have had on the findings are not discussed, for example married couples may differ in their interaction compared to interaction between a parent and son/ daughter. Also findings were not discussed in relation to age and the age of participants was not stated.

Summary

As compression of morbidity has not yet accompanied increasing life expectancy in later life in many countries across the globe (European Commission 2009), more older spouses will be living with long-term conditions as well as caring for a partner who also has complex morbidities (Pickard et al, 2012). Illness and disability do not only affect the individual but also affect partners and other family members in terms of their relationship, help-seeking behaviour and need for practical support in everyday life (Torge, 2013). For example, a UK survey of over 2,700 people affected by stroke revealed that two thirds of carers who were spouses or partners experienced difficulties in their relationship with the stroke survivor (Stroke Association 2013). Using individual interviews to capture narratives of chronic illness experience leads to construction of perspectives based on the individual, which in turn contributes to health and social care services directed at individual carers or care

recipients rather than focusing on couple's needs as a unit (Torge, 2013). Joint interviewing with couples presents an alternative methodological approach and its use in research on health and illness is increasing. However the majority of these studies focus mainly on the content of narratives and there are only a small number of studies that analyse the interaction and narrative styles between two participants which can produce rich data on self-presentation and co-construction of meaning in relation to chronic illness.

The few studies that have focused on interaction as well as content in their analysis of joint interview data have identified largely collaborative narrative styles (Bjornholtand and Farstad 2014; Sakellariou, Boniface et al. 2013; Torge 2013; Morris 2001, Polak and Green, 2015). However studies have also identified some disagreements and contradictory interaction between couples (Torge 2013; Bjornholtand Farstad, 2014; Polak and Green, 2015) with some informal carers tending to take a dominant role (Manzo et al. 1995; Shakespeare 1993). However these studies have not employed a systematic and replicable method for analysing the interaction between couples. Veroff et al., (1993) developed a systematic coding scheme to analyse interaction between couples, based on six codes to be applied to each shift in speaker, identifying exchanges that are both conflictual and collaborative. This represents a systematic, practical method of analysis that ensures transparency, rigour and validity.

An analysis of language use in narratives is another approach to examining self-presentation in relation to chronic illness. Despite sociolinguistic literature examining language use and gender, there are few studies on language use in relation to gender and older age, particularly in relation to older people who are frail and in poorer health and therefore more marginalised, and no sociolinguistic studies have been identified that include people with aphasia. There is also a lack of research comparing the use of individual and joint interviews in a health context. The study by Seale et al (2008) is the only one identified that has conducted a systematic comparison of individual and joint interviews, although one major limitation is that the study does not discuss age and the impact this may have on findings. As discussed in Chapter Two, old age is an important focus for health and social care professionals and policy-makers as the population is ageing and increasing numbers of older people are living and coping

with chronic illness, and, as stated, are often living in interdependent spousal relationships.

It is essential that research addresses the gap in our understanding of both the interaction and language use in chronic illness narratives co-constructed by older couples in joint interviews, as well as the content. Using a systematic method for the analysis of language, style and content of joint interview data will provide a rigorous and novel approach to understanding the impact of chronic illness for older couples who have shared their lives for many years. This will contribute to an understanding of how older couples manage chronic illness and the impact on couple identities and relationships, which will inevitably affect their health and social care needs and use of services.

Aims

The aim of this thesis, is to examine the experience and meaning of stroke in relation to the self-identity of people of advanced older age based on a biographical-narrative approach. Chapter One has highlighted the value of a biographical approach and has discussed the usefulness of Giddens's (1991) theory and Goffman's work as theoretical frameworks to understand self-identity following stroke in advanced older age. This thesis draws on Giddens's (1991) notion of identity as a set of reflexive biographical narratives in examining the impact of stroke on self-identity. The thesis critically assesses the relevance of the theory of biographical disruption (Bury, 1982) and the concept of narrative reconstruction (Williams, 1984), among others, in relation to the meaning of stroke for people of advanced older age living in urban, inner city areas. I also draw on Goffman's (1959) conceptualisation of identity as constructed through everyday interaction to explore the way in which participants in individual and joint interviews engage in self-presentation following stroke. Participants are likely to have experienced other significant hardships in their life such as the Second World War, financial hardships, and other health problems which may be important in mediating their experience of stroke.

Chapter Two has highlighted the need for further research on how couples interact and engage in the construction of joint chronic illness narratives. I argue that the meanings and disruption consequent on chronic illness need to be considered together for both the person with chronic illness and their spouse, and to focus not only on *what* is said in terms of the content of talk but also to analyse the style of the narrative, in terms of *how* people talk. The few studies that have focused on the interaction and language use in the co-construction of narratives lack a systematic and detailed method of analysis. Therefore this thesis aims to analyse joint interview data based on a rigorous and systematic method to study interaction and language use in co-constructed chronic illness narratives, drawing on the methods of Veroff et al (1995) and Seale et al (2008). I examine the ways in which older couples engage in the co-construction of narratives to make sense of the stroke based on joint interviews with stroke survivors and their spouses. This study therefore aims to broaden an understanding of the experiences and meanings of living with stroke for those of advanced older age and the impact of stroke on identity in the longer term.

Research Aim

This thesis aims to examine the experience and meaning of stroke in relation to the self-identity of people of advanced older age based on a biographical-narrative approach.

Research questions

1. How do older people talk about themselves following a stroke?
2. To what extent is stroke experienced and interpreted as a biographical disruption by people of advanced older age?

The two questions above will be addressed based on analysis of the biographical narrative interviews to identify the salient themes of participants' identity.

3. How do older couples present themselves following a stroke?

This question will be addressed based on analysis of couples' interaction and narrative styles in joint interviews (Veroff et al., 1993).

4. In what ways do older couples engage in the co-construction of narratives to make sense of the stroke?

This question will be addressed drawing on a sociolinguistic approach based on comparative keyword analysis techniques (Seale et al., 2006), in addition to the analysis of interaction and narrative styles of couples in joint interviews (Veroff et al., 1993).

This analysis will address the following sub questions:

5. Does gender influence the amount participants speak and how often in individual and joint interviews?

6. Does gender influence reference to personal experiences and shared experiences in individual and joint interviews?
7. Does stroke status (stroke survivors or spouse) influence participation in narrative construction in the joint interviews?
8. Does gender influence participation in the narrative according to narrative type (drawing on Veroff et al.'s, 1993 coding) in joint interviews?

Chapter 3: Methods

Introduction

The aim of this thesis is to examine from a sociological perspective the experience and meaning of stroke in relation to the self-identity of people of advanced older age based on biographical-narrative interviews. This chapter begins by discussing the setting and sample. I then discuss the theoretical sampling approach which led to the recruitment of spouses of stroke survivors in order to conduct joint interviews in addition to interviews with individual stroke survivors. The recruitment process is presented followed by a discussion of the biographical narrative approach to interviewing and the data collection process. The analysis section discusses the three distinct approaches to analysis; thematic analysis; analysis of interaction between couples; and comparative keyword analysis based on a sociolinguistic approach.

Setting and sample

A sample of stroke survivors (and spouses) were recruited from the South London Stroke Register (SLSR) which is an ongoing population-based register established in 1995 at King's College London (Wang, Rudd et al. 2013), as discussed. The SLSR records first ever stroke in patients of all age groups in a defined area of Lambeth and Southwark, which are both in the top twenty percent of the most deprived areas in England. Southwark and Lambeth are densely populated areas with high levels of ethnic diversity. Forty-six percent of the population in Southwark and 32% in Lambeth are from ethnic backgrounds other than white British, compared to only 15% in England and Wales overall (2011 census data from Southwark.gov.uk and Lambeth.gov.uk). Both boroughs have a relatively young population due to high numbers of working age people. Although younger age groups living in these areas are more ethnically diverse, older age groups are less so; in Lambeth 65% of the population aged 60 and over are White, 16% are Black Caribbean and 7% are Black African (2011 census data from Lambeth.gov.uk). In terms of household tenure the largest proportion of the population live in properties rented from the Council or a Housing Association (44% in Southwark and 34% in Lambeth compared to only 18%

in England overall) (2011 census data from Southwark.gov.uk and Lambeth.gov.uk), with Southwark council the largest social landlord in London (Jensen and Gidley 2016). The main housing type in both boroughs are flats and maisonettes (77% in Southwark compared to only 21% in England as a whole) (2011 census data from Southwark.gov.uk). This reflects the number of people living in the many tower blocks built in Southwark and Lambeth during the 1960s and 1970s. These were built to address the high demand for housing in the boroughs partly due to the slum clearance that began before the Second World War to improve living conditions, and due to the devastation caused by bombing during the War in parts of the boroughs, as in other inner city areas of London (Boast 2000).

SLSR participants are identified, through multiple notification sources, to be included on the register at the time of their stroke (Stewart et al, 1999). There are approximately 4,000 patients currently registered, 1,800 of whom are living. Participants are followed up by a fieldworker administering a questionnaire (or a postal self-completion questionnaire) at three months post stroke and then annually.

Stroke survivors invited to participate were aged 75 and over, living in private households (ie. not institutionalised) and at least six months post-stroke to ensure adequate time for participants to adjust to changed circumstances after an initial period of physical recovery. Other criteria for recruitment were an Abbreviated Mental Test (AMT) score of seven or above as indicated on the SLSR to exclude those with severe cognitive impairment or memory problems; ability to communicate in English; and the absence of severe aphasia (communication impairment), as identified by SLSR fieldworkers. Due to the nature of the biographical narrative interviews it was decided that those with severe cognitive impairment, severe memory problems or severe aphasia would experience significant challenges or be unable to participate in the interview. However participants with moderate aphasia were included, this may involve, for example, some stuttering, slurring or the occasional use of an incorrect word. People with aphasia are often excluded from research and therefore their perspectives can be overlooked based on assumptions about their inability to communicate (Dalemans, de Witte et al. 2010) therefore it is essential that they are included in research as far as possible.

Sampling approach

A theoretical sampling approach was taken in order to focus on a group of interest that emerged from the data as analysis progressed. The analysis of the interview data was therefore carried out simultaneously with data collection.

Invitation letters to participate in interviews stated that stroke survivors may have a relative or friend present at the interview if they wished. Of the first 12 interviews carried out, two included interviews where spouses (who were also informal carers) participated. Rather than playing the role of a spectator or providing occasional support, the spouses played an important role in constructing the narrative and the interviews took the form of 'joint interviews'. The analysis of these interviews as joint narratives constructed together by the couple, raised important issues not only about the experience of spousal caring, but about how married couples share the experience of stroke, and make sense of it together through their narratives, and the way in which the narratives were co-constructed. Relatively few studies have been carried out focusing on couples' co-construction and presentation of joint illness narratives, despite many older people living as a couple. This initial analysis, based on the couples as a unit of analysis, fed into the theoretical sampling strategy. Therefore I began to recruit stroke survivors who were married in order to carry out joint interviews with couples in addition to carrying out individual interviews with stroke survivors. This methodological approach of conducting joint interviews fitted well with the theoretical framework of this thesis, drawing on Goffman's (1959) notion that identity is constructed during social interactions and language in everyday life through the presentation of self. Joint interviews provide an opportunity to observe how couples 'perform' together and offer important insights into the interactions and nature of (power) relationships between stroke survivors and their spouses, not readily obtainable through other research methods (Allan 1980, Pahl 1989).

Recruitment

Ethical approval for this study was obtained from Bromley NHS research ethics committee (reference 08/H0805/5) (see Appendix E, page 329).

A total of 69 eligible SLSR patients were sent a participant information sheet (see appendix B, page 324) by post and an invitation letter (see appendix A, page 322) to participate in an interview about the experience of their stroke together with 'a relative or friend', if applicable, and if they wished. Letters were signed by Professor Charles Wolfe as Director of the SLSR, on behalf of the research student. A reply slip was included, to be returned to the student to indicate interest in participating and whether or not they wanted a relative or friend present, and a freepost return envelope was included.

Recruitment was carried out in four stages at different time points (see table 1, page 64). Those who returned the reply slip were contacted by phone to discuss the research and the interview process. If participants were willing to participate a date and time was arranged that was convenient for the stroke survivor. Two weeks after the letters were posted a follow up phone call was made to those who did not return the reply slips.

After carrying out two joint interviews (as part of the initial 12 interviews), I took the theoretical sampling decision to carry out more joint interviews with stroke survivors together with their spouses. From May 2009, at the third stage of recruitment (see table 1, page 64) I began to actively recruit SLSR patients who were married. As the SLSR does not record patients' marital status or who they live with I hand-searched the data for eligible patients with a spouse as next of kin on their initial SLSR form that records contact details. The same invitation letter was sent to married stroke survivors and invited them to have a relative or friend present if they wished. Therefore the decision about whether to participate in an individual or joint interview with their spouse could be made by the stroke survivors.

It was not possible to contact 35 stroke survivors due to an incorrect phone number or no answer when calling, reflecting the attrition in longitudinal studies, especially among older participants with poor health (Chatfield, Brayne et al. 2005). Only seven stroke survivors declined to participate due to ill health. From the 69 stroke survivors who were invited to participate in an interview, 27 participated either alone or with their spouse. A total of 27 interviews were carried out with 40 participants (27 stroke survivors and 13 spouses).

Table 1 . Stages of recruitment

Stage	Month, year	Number of SLSR patients sent an invitation letter	Number contacted through follow up phone call	Number of refusals to participate	Number of stroke survivors participating in interviews	Number of spouses participating in joint interviews
1	March 2008	5	5	0	5 (includes 2 pilot interviews)	0
2	Dec 2008	20	9	2	7	2
3	May 2009	15	12	3	9	8
4	June 2010	29	8	2	6	3
<i>Total</i>	-	<i>69</i>	<i>34</i>	<i>7</i>	27 (14 individual interviews, 13 joint interviews)	13

Biographical narrative approach

The method used in this thesis links to the theoretical perspective that identity is constructed through the process of creating and maintaining biographical narratives, i.e. the stories we tell about ourselves to make sense of our lives and to integrate life events. This draws on Giddens's (1991) notion of self-identity as a set of reflexive biographical narratives referring to the story of who we are and how we came to be where we are now. Therefore this thesis draws on the biographical narrative interview method, developed by (Rosenthal 2004) as this aims to elicit a detailed biographical narrative through very open questioning. This allows participants the freedom to structure their own narrative and to discuss the issues that are important to them and their identity.

Narrative and biography have provided the framework for a number of studies on the meaning and experience of chronic illness within the sociology of health and illness, as discussed in Chapter One. However these are generally based on a broad approach to biographical research and the methodology is often not explicitly described. The biographical narrative interview method specifically aims to elicit a construction of past events and sequences influenced by the present perspective of the participant. This approach aims to take the whole life story into account, in terms of the events experienced and how the story of these events is constructed. Therefore the interview should begin with an open question asking the participant about their life, giving them as much space as possible to tell their life story, without thematic restrictions. The example of the initial open question provided by Rosenthal (2004) begins 'Please tell me your family story and your personal life story; I am interested in your whole life. Anything that occurs to you. You have as much time as you like...' (2004: 51). The aim is that this then elicits a period of biographical narration from the participant lasting potentially several hours, not to be interrupted by the interviewer although general expressions of interest can be used to encourage narration. Rather than asking about aspects of identity explicitly and imposing a structure on the interview, the method aims to encourage a detailed narrative of the memories, experiences and feelings of the participant, and so important aspects of their identity will emerge during the narrative.

The main narration is then followed up with narrative questions to encourage the participant to talk about the phases or events in their life rather than asking about reasons or attitudes. Here Rosenthal (2004) distinguishes between internal narrative questions and external narrative questions. Internal narrative questions should follow straight on from the main narration period of the interview as these focus on themes already discussed by the participant and should be based on the notes taken during the main narration. The last stage of the interview process involves asking external narrative questions concerning topics of interest that have not yet been discussed. These should be asked in the last part of the interview to avoid the interviewer imposing his/her own interests on the participant.

Data collection

Pilot interviews

Although the method outlined by Rosenthal (2004) involves a very open, unstructured approach to biographical narrative interviews, she acknowledges that a more structured form of interview may be appropriate, combining the life history approach with a thematic focus. In order to investigate whether this method of interviewing was feasible I carried out two pilot interviews. These began with an open question informing the participant that the main topic of interest is the stories of people who have had a stroke, but the aim was to allow freedom to discuss other 'biographical strands', such as relationships with relatives, or the experience of other illness or retirement;

'I am interested in the stories of people with stroke. Please tell me the story of your stroke, anything that occurs to you. You have as much time as you like. I won't ask you any questions for now. I will just make some notes on things that I would like to ask you more about later.'

The two interviews took place in participants' homes. Signed consent (see consent form in Appendix C, page 326) was given by the participants and interviews were digitally recorded. I took notes on particular points of interest throughout the main narration and then asked internal narrative questions focusing on the themes

discussed followed by external narrative questions on topics of interest that had not yet been discussed. To ensure details of the experience of stroke were captured a broad topic guide was used, based on research findings on the experience of stroke. This included questions on living with stroke, perceptions of stroke, social support and ways of coping with everyday issues (see appendix D, page 328).

During the pilot interviews the participants began their narrative with a focus on the stroke event and then discussed living and coping with stroke. Rosenthal (2004) advises against using questions like 'why...?' or 'what for?' during biographical narrative interviews to minimise the influence of the interviewer on the participant's wording and structuring. While carrying out the two pilot interviews I found that refraining from asking questions during the main narration period was initially a challenge. This was a contrast to my previous experience of qualitative interviewing taking a more traditional approach, following a structured or semi-structured format involving questioning and probing throughout using a topic guide. However as I carried out more interviews I became more at ease with the biographical narrative approach, beginning with a very open question. I gradually became more skilled at pulling out 'biographical strands' that I would make a note of during the main narration and then follow up with internal narrative questions. The participants in the pilot interviews would often talk about other topics in addition to stroke and other ill health, including their working life and bereavement. Following a structured or semi-structured approach to interviewing this may be viewed as 'off topic', and would normally be discouraged by the interviewer who would seek to bring the participants back to the topic in hand by asking specific questions. However, following the biographical narrative approach, this talk 'off topic' provided valuable data as these were the themes and experiences that were important to the participant and not imposed by the interviewer. Based on the approach used in the pilot interviews I continued to carry out the main interviews without making any changes to the method, as detailed in the next section.

Interviews with individual stroke survivors

The ethical implications of this study were considered at the beginning and during the data collection process. Because the participants were aged 75 and over, and

suffering from one or more chronic condition and were often frail and vulnerable it was particularly important to ensure that ethical procedures for informed consent were followed. An information sheet was posted to participants, with the invitation letter, stating the nature of the interviews and that the aim was to understand experiences of stroke in relation to other aspects of the lives of stroke survivors. When I phoned participants in response to their reply slip or as a follow up, I also explained the nature and aim of the research and what participation would involve and answered any questions.

The risk associated with being a lone researcher out in the field was considered. I ensured that a member of staff in my department knew where and when I had an interview arranged and had my contact details and I informed them whenever I had completed an interview. Following standard interview practice at the SLSR, all interviews were carried out at participants' homes at a date and time convenient for them. Before the interview I talked through the information sheet, ensuring that participants fully understood the nature of the research and what participation would involve and that the interview would be digitally recorded with their permission. They were made aware that their participation was voluntary and that they were free to withdraw at any time. I also stated that participating would not affect the standard of care they received, that the content of the interview would not be shared with any health service staff and that all identifiable data would be anonymised. I informed them that they would be able to take a break at any time during the interview if necessary. I would then check whether there was anything that was unclear or that they wanted me to tell them about again. I then gave them the opportunity to ask any questions before they signed the consent form. All participants were happy to sign the consent form and to be recorded. As all stroke survivors were participants on the SLSR they had previously signed a consent form to participate on the Register and were somewhat familiar with answering questions about their stroke as they were visited annually by an SLSR fieldworker to complete a questionnaire. Brief field notes were taken on demographic data (eg. age, ethnicity, marital status, housing status) and the general context of the interviews (eg. place of interview and brief impressions of immediate surroundings).

When I gave the participants an opportunity to ask any questions about the interview or the research, people sometimes asked about the study and about my role more

generally. Due to the informal nature of interviews and in an effort to develop rapport with participants and to ensure they felt at ease I would engage in casual conversation before and after the interview, often accepting offers of a cup of tea. I was sometimes shown photos of family members or photos taken during the Second World War and letters containing details of medical conditions or medication to illustrate health issues discussed during the interview.

Following the format of the pilot interviews, the main interviews began with an open question asking the participants to tell the story of their stroke, with the aim of eliciting a detailed narrative, indicating how participants made sense of the stroke, what meanings they attached to it, how they presented themselves and how they attempted to locate the stroke in their overall biography. The length of the period of the initial narration would vary depending on the participant and how at ease they were with minimal verbal interaction from the interviewer initially.

Participants generally began their narrative with a focus on the stroke event and then discussed living and coping with stroke before moving on to other themes. The main narrative was followed by some internal narrative questions that elicited more detail regarding themes already discussed by participants, based on brief notes taken during the main narration. For example if a participant talked about rehabilitation services they received after the stroke I would follow this up with questions asking for more detail. In the final part of the interview, external narrative questions were asked concerning topics of interest that had not previously been discussed. For example the date of their stroke, length of stay in hospital after the stroke or social support received from friends and family.

I anticipated that interviews discussing stroke and other related experiences may cover sensitive topics and that some may not feel at ease talking for long periods without interruption. Participants' reluctance to talk about traumatic and emotional events in their lives has been identified as a challenge when conducting biographical narrative interviews (Vajda 2007). I found that the majority of participants were very willing to talk freely and openly about their stroke and other related issues and most reported that they found it very beneficial to talk at length about their stroke within the context of their life. However one participant's daughter died just before she had a stroke and she talked about this as a possible cause of her stroke. She found this

issue very difficult to discuss and began to get upset during the interview. At this point I asked her if she would like to pause the interview which she agreed to. After a short break I ensured that she was willing to resume the interview. I then carefully managed the interview, still focusing on the topic of her stroke, but she did not bring up the topic of her daughter's death again, and I finished the interview on a positive note after discussing the good recovery she felt she had made after the stroke.

I anticipated that ill health, fatigue, loss of concentration, or memory problems were possible challenges for stroke survivors when participating in a biographical narrative interview. Although the majority of participants were comfortable to talk at length, with some appearing to find it somewhat cathartic, five participants were less able to engage in a detailed and lengthy biographical narrative. In contrast to others' more positive and stoical narratives, they appeared to be 'surviving' as they were in poorer health and were experiencing a certain amount of discomfort and pain (see page 95). These interviews were shorter in length and I had to probe these participants much more as the answers they gave were less detailed. Therefore the nature of these interviews differed to Rosenthal's ideal of the biographical narrative method, indicating that this approach may not be suitable for participants in poor health and discomfort.

The very open method of biographical narrative interviews allowed participants to structure their own narratives and enabled them to set their own boundaries according to the topics they felt comfortable discussing. I found that for most participants it was a method that put them at ease as they were able to discuss the issues that were important to them and many seemed to value the opportunity to tell their story. Based on her ethnographic research on the attitudes and experiences of health and illness of people living in the East End of London, Cornwell (1984) argues that asking participants direct questions, in line with structured interviews and questionnaire methods, produces what she refers to as public accounts. This contrasts with methods inviting people to tell a story which are more likely to lead to personal accounts. She argues that public accounts of health and illness are based on publically acceptable ideas and values in line with medical perspectives, and private accounts are more practical and pragmatic. Based on the present study, I would argue that there was often no clear distinction between personal and public accounts. However due to the open interview method many participants who engaged in a

biographical narrative gave accounts that appeared to be more 'personal' in nature in both the individual and joint interviews. For example some talked very openly about their relationships with family members, even when this involved negative feelings and experiences.

Joint interviews

The first 12 interviews carried out included two joint interviews with stroke survivors and their spouses that revealed important findings highlighting the shared experience of stroke, spousal care and the ways in which narratives can be co-constructed. Therefore, following a theoretical sampling approach, as outlined, I began to actively recruit married stroke survivors with the aim of carrying out joint interviews with couples to further examine these findings.

The same methodological process and ethical standards of conduct for individual interviews were followed when carrying out the joint interviews and signed consent was requested from both stroke survivors and spouses. The same opening question and broad topic guide was used, but both participants were invited to tell the story of the stroke. In the joint interviews the interactional dynamics between the couples and between the researcher and the couples frequently shifted throughout the interview. Spouses would often take it in turns to narrate, sometimes talking amongst themselves while trying to negotiate their narrative, and at other times one spouse would take a more dominant role. Due to the informal nature of the interview, participants would sometimes engage me in conversation (an example can be seen in figure 1, page 72). To encourage rapport I would participate in brief conversation and then allow the participants to continue talking.

Figure 1. Excerpt of a transcript illustrating conversation with the interviewer

Molly and David (ID15), discussing the street they live on during the Second World War

D: Oh people wouldn't live down this street

M: No it was shut off with bridges. We had a bridge that end of the street and a bridge that end of the street and when the boats used to come through the bridges would go up and you couldn't get off.

D: You couldn't get off. If you was about 5 minutes late to work, there was a bus to *** but you could wait there 20 minutes, half hour till that ship when through the lock at *** and that one used to be mainly for barges, that one up there. Once it swung you couldn't get over. And we went to work years ago there was no such thing as flexi time. Do you do flexi time?

E: No

D: Good! (laughs)... Well if you was 2 minutes late you lost a full hours pay. There you are.

M: That's why they moved us all off here didn't they, when the War was on.

D: Yeah, god yeah.

M: To get us all away otherwise we wouldn't have got out.

D: No cor blimey.

M: All the road was burning up.

D: 'Cause they would block roads out here. All over there was big oil tanks, all in there was timber. Have you ever seen photos of the blitz?

When conducting joint interviews I was aware that there may be issues of contention between husbands and wives or issues that participants may not wish to discuss in front of their spouse. If any direct conflict were to escalate between couples that may cause emotional harm to participants I planned to change the focus of the interview or suggest a break. Although conflict did arise for some couples during these interviews it appeared to be over relatively long-standing issues that had previously been discussed amongst the couples, for example one stroke survivor said he was independent enough to go out of the house by himself but his wife strongly disagreed, saying that his eyesight was too limited and it was dangerous for him to go out unaccompanied. By inviting stroke survivors to have their spouse (or another relative/informal carer) present if they wished this implicitly allowed the participant to choose whether or not to participate in a joint interview. Giving participants the option of individual or joint interviews when talking about potentially sensitive issues, such as chronic illness, is one recommended approach (Morris, 2001). However if stroke survivors are living with a spouse whom they are dependent on for care the circumstances may mean it would be difficult to be interviewed alone. All of the stroke survivors who choose to be interviewed together appeared to feel comfortable with each other and spoke openly.

On a practical level interviewing those who are chronically ill together with their spouse or informal carer may be more appealing to both participants as they may feel more comfortable and it may make it more socially acceptable for the participant with the chronic illness to take rests during the interview (Morris, 2001). It appeared that all of the stroke survivors choosing to be interviewed together appeared to feel very at ease with each other and for aphasic stroke survivors in particular, having a spouse to support their construction of narratives appeared to make them feel comfortable and gave them a break from talking for long periods. Being interviewed with their spouse may have also encouraged aphasic stroke survivors to consent to participate in the interview. It has been argued that joint interviews with patients and their informal carers, who are often spouses, give carers the opportunity to have a voice as they can often feel disempowered in the medical setting (Arksey, 1996; Morris, 2001). However a potential limitation is that couples who agree to participate in a joint interview may be more likely to engage in consensual rather than conflictual narratives (Arksey, 1996) or that carers may take a more dominant role during the interview (Manzo et al 1995; Shakespeare 1993) and speak on behalf of people who

are chronically ill, particularly those with aphasia. However, as discussed in the next section, the aim of two of the methods of analysis (focusing on interaction between couples and analysis from a sociolinguistic approach) is to examine these power dynamics and the ways in which narratives are co-constructed.

Analysis

In this section I present each of the three methods of analysis used; thematic analysis, analysis of interaction in joint interviews and analysis drawing on a sociolinguistic approach.

Thematic analysis

Thematic analysis was carried out to address the following research questions:

- How do older people talk about themselves following a stroke?
- To what extent is stroke experienced and interpreted as a biographical disruption by people of advanced older age?

An initial thematic analysis of the content of individual interviews (where the individual was the unit of analysis) and joint interviews (where the couple was the unit of analysis) was carried out to identify biographical narrative themes. The open biographical narrative interview method enabled participants to bring up topics important to them and their identity. The analysis began with transcribing all of the interviews verbatim from the audio recordings. All identifiable data were anonymised. The transcripts were saved in a password protected folder on the computer and hard copies of transcripts were kept in a locked filing cabinet. The transcribing process enabled familiarisation with the data. With interviews where participants slurred their words due to moderate aphasia and where participants had strong Caribbean accents, speech was sometimes hard to decipher. Joint interviews where participants would occasionally talk at the same time could also be difficult to decipher. These interview recordings had to be listened to repeatedly to ensure they were transcribed verbatim.

The transcripts and field notes were read in detail. Based on these I wrote a brief synopsis for each individual participant or couple summarising their background and circumstances. Each synopsis included interview ID number, pseudonyms, date of interview, date of participant's stroke, any disability or other issues experienced since the stroke, ethnicity, who they lived with and what contact they had with friends or family, whether they received any assistance from care workers, what type of housing they lived in, what other health conditions they had, previous occupation, and, for couples, how long they had been married. These synopses provided a useful preliminary reading of the data and an easily accessible format to set out background characteristics and circumstances of each participant or couple, before beginning formal analysis. Below in figure 2 is an example of a synopsis (see appendix F for synopses for all participants, page 333).

Figure 2. Example of a synopsis

ID15, Date of interview: 26.5.09: Molly (aged 75) and David (aged 81)

Molly had had a stroke in April 2007 while at home. At the same time her husband David had suffered angina pains which he felt had been brought on by the shock of seeing his wife have a stroke. He had previously had a heart attack and had a heart bypass operation. He called an ambulance for his wife then a relative also had to call an ambulance for him. Molly spent 6 days in hospital and received thrombolytic drugs and began to recover after this but they both said she's still 'not right' after the stroke. Molly said that there was 'something wrong' with her right leg that meant it was difficult for her to walk. She was unable to do anything around the home apart from putting the washing machine on and had to use a stick to walk with outside and had trouble walking upstairs. They had had a stair rail fitted and a shower with a chair installed instead of a bath. David now has to do all the cooking and cleaning and give her a bit of help with getting dressed. They said that before the stroke they used to enjoy going out on coach trips at weekends but could no longer do this. David was able to walk and move around unaided but in addition to having a heart condition he also had impaired sight as a result of macular age-related degeneration.

Molly and David were White British. Molly had been a cook in a pub and her husband had worked at the local Docks. They had three children and eight grandchildren and a few great grandchildren, a few of whom lived close by and helped them out, particularly their daughter. They also had a neighbour who took them shopping regularly. They lived in a house that they had bought under the 'right to buy' scheme during the 1980s. Molly had lived in the area all her life and David had lived there for most of his life and they talked about how much the area had changed over this time. They had been married for 58 years.

I then carried out a detailed reading of hard copies of each transcript to identify narrative themes that were important in participants' self-presentation. This was an inductive process, with common themes emerging from the narratives. I carried out open coding by writing code words or phrases in the margins of the transcripts to indicate themes. To develop a coding scheme I listed all code words or phrases and grouped them together with other common themes to form categories. Each category was identified by a high level code. For example code phrases 'financial problems with housing', 'problems with anti-social behaviour' and 'lack of community' were all categorised together under the higher level code 'housing and community'. Four main overarching themes were identified; participants' experiences of stroke (and other ill health to a certain extent); work and retirement; bereavement and loneliness; housing and community. An excerpt of coded transcript using the scheme can be seen in figure 3 (page 78).

Figure 3. Excerpt of a transcript coded thematically

Delia (ID 12)

<p><i>Coding:</i> <i>Stroke</i></p>	<p>I'm interested in, if the statins or the things for bringing down your blood pressure are making me feel worse than I would normally feel because I felt fine before when I had my high blood pressure. I didn't feel ill um. I just feel slightly out of control now really. I think it's partly to do with what's happened to my brain. It's partly slight wooziness. Like when I go to cross the road which I do very cautiously I turn my head one way and look and then turn the other way and look I feel a little bit out of balance all the time, still. Because (<i>the stroke</i>) did get the balance part of my brain and my GP said she thought it would never get better that bit, you know might get a bit better but not completely better. Um I mean, you know, you have to keep coming to terms with the fact that you can't do what you used to do. You've got this pain which nobody can</p>
<p><i>Loneliness</i> <i>(lack of social support)</i></p>	<p>see, it hurts you know....quite often I don't see enough of people. I mean I do see people, like there was a lovely cleaner who was here and then I went to see my friend Carol but I suppose I am sort of suffering from the fact that I don't have a partner who'll help me look after myself and who I can help. You know so that's the tough bit really. If you're well, it doesn't matter how old you are or anything, what matters is that you can get up and walk out and do things and everything but when you can't um when you can't easily you're much more vulnerable I think.</p>

The number of different codes in each category were counted for each interview (see Appendix G, page 355). Each of the participants presented different narrative topics that represented multiple aspects of their identity. The salience of themes were identified according to the amount they arose during the interview (based on the number of codes) and also the prominence participants gave to themes by bringing them up without prompting. Although many qualitative researchers may not use the approach of counting themes and categories, this is recommended as a useful approach for providing an understanding of the data as a whole (Silverman 2010). I also argue that this is a particularly useful approach for biographical narrative interview data as participants bring up topics without being prompted. Interviews were categorised based on the salience of each of the four overarching themes (see table 2, page 80).

Table 2. Dominant themes of self-presentation

The table gives the four main overarching themes from the narratives in each of the columns, listing participants according to the main theme/s of their narrative.

Stroke	Work and retirement	Loneliness and bereavement	Housing and community
Ted (and Rita)*	Ted (and Rita*)		Ted (and Rita*)
Patrick (and Betty)*	Patrick (and Betty)*		Patrick (and Betty)*
	Sheila*	Sheila*	
Sarah (and Nelson)*	Sarah (and Nelson)*		
Paul			
Grace (and Simon)			
Gloria			
Helen (and John)			
Jack (and Penny)			
Molly (and David)			
Leonard			
Martha			
Tony (and Cathy)			
Hilary (and Adam)			
Gretal (and Vas)			
Tom (and Nora)			
	Bob		
	Mary		
	Eric (and Irene)		
	Tim		
		Alfred	
		Rose	
		Derek	
		Joan	
		Delia	
			Richard (and Judy)
			Ethel

The interviews of four stroke survivors (three of whom were interviewed with their spouse) were identified as not having one main theme that emerged more prominently than others and were categorised under multiple themes (indicated by an asterisk in table 3). Although all participants discussed the stroke, some focused on other themes in more detail, or focused on the stroke in relation to another theme such as work or loneliness. These themes represented multiple aspects of identity.

For the purposes of the thematic analysis joint interviews were treated as a whole. Further analysis was carried out on the joint interview data to examine the meanings and disruption of stroke for both the stroke survivor and their spouse as well as interaction between spouses, as discussed in the next section.

Analysis of joint interviews

Joint interviews were analysed using an additional method to address the following research question:

- How do older couples present themselves following a stroke?

In line with Goffman's (1959) notion that identity is constructed during social interactions and language in everyday life through the presentation of self, analysis of joint interviews was carried out to identify different styles of couple interaction, referring to *how* couples co-constructed their narratives. A coding scheme was employed with a focus on couples' co-presentation in terms of the structure of narratives and interaction. This was informed by a systematic coding scheme developed by Veroff et al. (1993) to analyse joint interviews with newlywed couples and involved coding each shift in speaker as one of six types of interaction:

1. Collaboration: *extending the idea of the spouse, questioning for information, answering questions that further the story or continuing a storyline that the spouse had previously begun.*
2. Confirmation: *a statement of agreement e.g. 'yes' or 'um-hmm'.*
3. Confirmation-collaboration: *an interruption that affirms the previous statement of the spouse and then adds new material.*

4. Conflict: *disagreeing or interrupting the spouse with a negative response.*
5. Non-response: *explicitly avoiding responding to the spouse's previous comment.*
6. Continuation: *continuing the narrative without reflecting on the previous comment from the spouse.*

The first three types of interaction were categorised as collaborative styles of narratives and the last three as (explicit or implicit) conflictual styles. Transcripts were read in detail and each shift in speaker was coded according to the types above. This involved writing a code in the margins next to each shift in speaker on a hard copy of each interview transcript. This coding process took time as all words spoken in the transcripts had to be read in detail. However the more transcripts I coded, the more familiar I became with the coding scheme and the more efficient I became at carrying out the analysis. The number of each code used was then counted by hand for every transcript, and recorded in an Excel spreadsheet. An example of the coding based on an excerpt presented earlier can be seen in figure 4 (page 83). Based on the frequency of each code, joint interviews with the highest number of collaborative codes from all of the joint interviews were categorised as mainly collaborative and those with the highest number of conflictual codes from all of the joint interviews were categorised as mainly conflictual.

Figure 4. Excerpt of a transcript coded using Veroff et al.'s (1995) coding scheme - Molly and David (ID15), discussing their street during the World War Two

Confirmation-collaboration	D: Oh people wouldn't live down this street
Confirmation-collaboration	M: No it was shut off with bridges. We had a bridge that end of the street and a bridge that end of the street and when the boats used to come through the bridges would go up and you couldn't get off.
Confirmation-collaboration	D: You couldn't get off. If you was about 5 minutes late to work, there was a bus to *** but you could wait there 20 minutes, half hour till that ship when through the lock at *** and that one used to be mainly for barges, that one up there. Once it swung you couldn't get over. And we went to work years ago there was no such thing as flexi time. Do you do flexi time?
	E: No
Collaboration	D: Good! (laughs)... Well if you was 2 minutes late you lost a full hours pay. There you are.
Confirmation	M: That's why they moved us all off here didn't they, when the war was on.
Collaboration	D: Yeah, god yeah.
Confirmation	M: To get us all away otherwise we wouldn't have got out.
Collaboration	D: No cor blimey.
Collaboration	M: All the road was burning up.
	D: 'Cause they would block roads out here. All over there was big oil tanks, all in there was timber. Have you ever seen photos of the blitz?

Building on this analysis identifying couple's narrative styles, the content of interviews was also taken into account to develop further codes and ideas about the data, providing a further layer of analysis. This involved detailed readings of sequences of transcripts coded as conflictual and collaborative interaction based on Veroff et al.'s (1993) coding scheme, to examine the content of the transcript to identify themes of co-presentation in relation to narrative styles. Codes were developed and built on to identify types of co-presentation of identity underpinned by particular narrative styles (see Appendix H, page 357). This was an iterative analytical process carried out in close critical discussion with my supervisors, Professor Myfanwy Morgan and Professor Karen Lowton, which enhanced rigour and validity. From this analysis three main types of co-presentation of identity were identified; 'united couple', 'positive carer' and 'frustrated carer', discussed in detail in Chapter Six.

Comparative keyword analysis

Joint and individual interview data were analysed using a third approach to address the following research question:

- In what ways do older couples engage in the co-construction of narratives to make sense of the stroke?

In line with the theoretical framework of this thesis, Goffman (1959) demonstrates the significant role of language and social interaction in everyday life for the construction of self-identity. Following this social constructionist approach, sociolinguistic analysis examines discourse in its wider socio-cultural context, focusing on the way in which social meanings, social relationships and social identities are constructed and reinforced. A sociolinguistic approach to analysis focuses on a range of aspects of language including content, narrative structure, humour, turn-taking patterns and use of pronouns.

Drawing on a sociolinguistic approach a further method of analysis was applied to both individual and joint interview data. This analysis was based on the comparative keyword analysis technique developed by Seale, Ziebland et al. (2006) to enable a

transparent and rigorous comparative analysis of joint and individual interviews that is both replicable and objective. The number of singular and plural pronouns spoken by each participant were coded and counted in the 14 individual interviews and the 13 couple interviews. Singular pronouns (I, me, my, mine) indicate talk about personal experience and plural pronouns (our, we, we've, we're, us) indicate talk about shared experience. The number of words and number of turns taken to speak by men, women and the interviewer were coded and counted for all individual and couple interviews.

Also drawing on previous analysis based on Veroff et al.'s (1993) methods, joint interviews were categorised according to narrative type (ie. mainly collaborative, mainly conflictual, or collaborative on a continuum), as presented on page 81. Each narrative type was explored in relation to number of words spoken, number of turns taken, and number of singular and plural pronouns used. Differences in the construction of narratives were also explored in relation to gender and status as a stroke survivor or spouse. The specific steps in analysis are outlined below.

Steps in analysis

a. Using the 'word count' function in Microsoft Word the total number of words for each transcript were calculated. All interview transcripts were then imported into NVivo software and all words spoken by the participants were coded according to the gender of the speaker (ie. 'male' or 'female') or as 'interviewer'. Using NVivo to identify the 'percentage of coverage' for each transcript for male, female and interviewer codes, the number of words for each participant was calculated from the total word count. Using the 'number of references' for the male, female and interviewer codes in NVivo, the number of turns each participant took during the interview was recorded. All numerical data was recorded in an Excel spreadsheet according to gender and participant status (ie. stroke survivor/ spouse) and means were calculated.

b. In each transcript singular pronouns (I, me, my, mine, he, she) and plural pronouns (our, we, we've, we're, us) were identified using the advanced search function in Word. Each transcript was searched and the number of each pronoun was manually counted for every participant. For the joint interview transcripts the number of

pronouns was counted individually for husbands and wives. All numerical data was recorded in an Excel spreadsheet. The total number of singular and plural pronouns was then calculated and means were calculated.

c. Joint interviews were categorised based on narrative type according to previous analysis (as presented on page 81) drawing on Veroff et al's (1993) method, ie. mainly collaborative, mainly conflictual, or 'collaborative on a continuum'. For the purposes of this analysis collaborative couples were divided into 'collaborative' or 'collaborative on a continuum'. Couples identified as having a 'collaborative' narrative type were based on transcripts coded with mainly collaborative codes with the fewest conflictual codes (5% or less), and all couples displayed strong co-presentations as a 'united couple' (see page 192). Couples identified as having a 'collaborative on a continuum' narrative type were based on transcripts that were mainly collaborative but with more conflictual codes than the couples identified as 'collaborative'.

d. Comparisons of the number of words spoken, the number of turns taken, and the number of singular and plural pronouns used were then made across individual and couple interviews in relation to gender, participant status and narrative type.

e. Numerical data was entered into SPSS and a Chi square analysis was conducted to investigate the relationship between number of words spoken, number of turns taken, number of plural pronouns used and number of singular pronouns used in relation to gender, status as a stroke survivor or spouse and type of narrative (ie. mainly collaborative, mainly conflictual, or collaborative on a continuum). However results indicated no significant relationships due to a small sample therefore the findings presented in Chapter Six focus on the patterns indicated by the comparative keyword analysis.

This chapter has discussed the biographical narrative interviews conducted with stroke survivors and their spouses and the three methods of analysis carried out to examine the self-identity of people of advanced older age after stroke. Reflections on the process of interviewing and a more detailed discussion of the methodological and ethical challenges are presented in Chapter Seven. The next three chapters present the findings from each of these methods in sequence, beginning with the findings from the thematic analysis.

Chapter 4: Findings: Stroke and self-presentation

Introduction

This chapter examines the identity of stroke survivors aged 75 and over through an analysis of participants' themes of self-presentation. This draws on Goffman's (1959) notion that identity is constructed during social interactions in everyday life through self-presentation and Giddens' (1991) concept of the self as a set of reflexive biographical narratives that continually integrate life events in the external world. This chapter will focus on each of the interviews taken as a whole and Chapter Five will present a more detailed analysis of the joint interviews. I first describe the characteristics of the study group and then examine participants self-presentation based on a thematic analysis of interviews with 27 stroke survivors (and 13 spouses participating in joint interviews). The first section examines the four dominant themes of self-presentation identified in participants' accounts when asked 'can you tell me the story of your stroke?' (see table 2, page 80). This open question aimed to elicit a detailed narrative, indicating how participants made sense of the stroke, what meanings they attached to it, how they presented themselves and how they attempted to locate the stroke in their overall biography. I then examine how stroke was perceived in relation to other life experiences and aspects of biography with a particular focus on those who described stroke as a disruption to biography and their process of narrative reconstruction.

Characteristics of participants

Twenty-seven stroke survivors participated in interviews and thirteen of them were interviewed jointly with their spouses.

Table 3 (see page 91) provides an overview of the demographic characteristics of participants. Fifteen stroke survivors were women, 12 were men. All stroke survivors were aged 75-87 years and their spouses aged 59-85. Although all participants were now retired, the majority were from a working class background and had previously mainly worked in semi-routine and routine occupations based on the Standard

Occupational Classification (Office for National Statistics, 2010). Men had been employed in manual occupations such as factory worker, dock worker and delivery driver. All the women had worked at some point during their lives, also mainly in manual occupations such as cleaners, cooks, cashiers and factory workers. Many had been employed by local businesses therefore working in close proximity to where they lived. Two individual participants (Delia, Martha) and two female stroke survivors and their husbands (Helen and John, Hilary and Adam) were previously employed in occupations categorised as managerial, administrative and professional (Office for National Statistics, 2010).

The majority of participants were White British. Paul, Leonard, Gloria, Grace and Simon were Black Caribbean; Sarah and Nelson were Black African; Patrick, Eric and Irene were Irish; and Martha was Eastern European.

Participants mainly lived in inner-city urban areas in South London with many living in or near the area in which they had been born, with a few describing themselves as 'Bermondsey born and bred' and 'Lambeth born and bred'. The majority lived in flats on estates built after the Second World War that were rented from the council or a Housing Association. Seven stroke survivors lived in owner-occupied housing. One individual participant and three couples had bought their flats under the 'Right to Buy' scheme in the 1980s. The majority had lived in the same property for most of their adult lives and had brought up their children there. They were therefore very familiar with their local area and over the years they had grown to know their neighbours well. Some participants discussed the role they had played in their neighbourhood and local community over the years. Some also talked about the changes they had witnessed to their local area over their lifetime in relation to the perceived decline in standards of their local environment and feeling that there was a lack of 'community spirit'. However a few participants commented that they would not want to move out of the area as they were so familiar with their neighbourhood because they had lived there for so long.

Two of the individual interview participants were married (Tim and Leonard) with the other 12 living alone. Ten of the individual participants had experienced the death of a spouse, most in recent years. All of the participants in joint interviews lived together as a couple without any other relatives living with them. Couples had been married

for 20-65 years. All but two of the individual participants and all but two of the couples had children and grandchildren. Many saw their children and grandchildren quite often although they did not live nearby. Some participants, particularly those who lived alone, talked about the practical support that their children and grandchildren provided, for example helping them with shopping, cleaning, and driving them to places. The majority of participants had experienced the death of loved ones, including friends, neighbours, spouses and children.

The time since the participants' stroke was quite varied, ranging from six months to 15 years, although 21 of the participants experienced their stroke within the last three years. Time spent in hospital post-stroke also varied with some only spending one or two nights and others with more severe disability staying several months. There were also variations in levels of aftercare received, with some reporting that they had had physiotherapy, occupational therapy, speech therapy and home adaptations after their stroke but others reporting that they did not receive any of these services. Participants' level of disability after the stroke varied. Some reported that they were 'slower' after the stroke and could not walk as far and some reported having a worse memory since the stroke. Nine stroke survivors used a stick or a walking frame to walk. Six of the stroke survivors were severely disabled and used a wheelchair, four of whom rarely left their home. Five stroke survivors, two of whom were living with a spouse, were currently receiving assistance with personal care from care workers. Five stroke survivors had moderate aphasia. Tom and Sarah had a form of aphasia referred to as dysarthria characterised by slurring or thickness of ordinary speech. Paul, Tony and Martha had a form of aphasia referred to as expressive dysphasia characterised by difficulty finding the right words to express thoughts.

All stroke survivors had multiple chronic conditions which contributed to their level of disability and ill health. The most common conditions were diabetes, arthritis and heart conditions. Although the spouses were generally in better health, with all but one able to walk unaided, eight had at least one chronic condition, also mainly diabetes, arthritis and heart conditions.

This group of older participants had all lived through the Second World War, and all lived in economically deprived inner city areas, with the majority living in the same area for their whole lives, having raised their families there. Most were from working

class backgrounds and had worked in manual occupations. All were older, aged 75-87, living with a certain amount of ill health, including stroke and other chronic conditions. Therefore, overall this group may be regarded as being in the 'fourth age', a period of old age characterised by serious illness, functional decline, frailty and physical dependence (Laslett, 1989). However this was not how many of the participants presented themselves, as discussed in the next section.

Table 3. Participant characteristics (stroke survivors in bold, spouses not in bold)

<i>Pseudonym</i>	<i>Age</i>	<i>Years married/ marital status</i>	<i>Years post stroke (approx)</i>	<i>Previous occupation</i>	<i>Ethnicity</i>	<i>Main health conditions (other than stroke) / mobility</i>
Patrick	85	58	1	Van driver	White Irish	Hearing impairment, walks unaided
Betty	83			Bookmaker's cashier	White British	Osteoporosis, walks unaided
Jack	79	30	1	Builder	White British	Walking frame and wheelchair user
Penny	59			Housewife	White British	Walks unaided
Molly	75	58	2	Cook	White British	Walks short distances unaided
David	81			Shipyard worker	White British	Heart condition, sight impairment, walks unaided
Ted	84	65	2.5	Factory worker	White British	Severe sight impairment (registered blind), walks unaided
Rita	83			Cook	White British	Heart condition, severe arthritis, walks unaided
Sarah	76	60	1	Laundrette worker	Black African	Mild aphasia, wheelchair user
Nelson	77			Train conductor	Black African	Depression, walks unaided
Helen	84	46	11	Church social worker	White British	Diabetes, wheelchair user
John	85			Business consultant	White British	Osteoarthritis, heart condition, wheelchair user
Tony	75	50	1	Butcher	White British	Mild aphasia, Heart condition, walks short distances unaided
Cathy	74			Sales assistant	White British	Walks unaided, partially deaf
Richard	83	32	3	Delivery driver	White British	Severe sight impairment (registered blind), diabetes, wheelchair user
Judy	68			Administrator	White British	Diabetes, walks unaided
Hilary	79	52	2	Designer	White British	Walks short distances unaided
Adam	80			Judge	White British	Walks unaided
Grace	78	20	12	Home carer	Black Caribbean	Walking frame and wheelchair user

Simon	75			Hospital porter	Black Caribbean	Prostate problem, walks unaided
Gretal	78	50	1.5	Nursery school teacher	German	Uses walking stick
Vas	80			Waiter	Greek Cypriot	Walks unaided
Tom	80	48	12	Warehouse worker	White British	Mild aphasia, Prostate problem, mild aphasia, walks short distances unaided
Nora	78			Cook	White British	Transient ischaemic attack, walks unaided
Eric	79	50	15	Builder	White Irish	Diabetes, walks short distances unaided
Irene	77			Housewife	White Irish	Walks unaided
Rose	84	Widowed	1.5	Bookkeeper	White British	Can walk a very short distance unaided
Bob	87	Widowed	0.5	Concierge	White British	Arthritis, Uses walking stick indoors, Unable to walk outside
Mary	75	Widowed	7	Cleaner	White British	Severe sight impairment, able to walk unaided
Tim	75	Married	2	Electrician	White British	Walks unaided with difficulty
Leonard	80	Married	1.5	Carpenter	Black Caribbean	Uses a walking frame
Paul	79	Widowed	1.5	Delivery driver	Black Caribbean	Mild aphasia, severely disabled, housebound
Delia	75	Divorced	1.5	Art teacher	White British	Walks short distanced unaided, vocal cords affected by stroke
Martha	79	Widowed	2.5	Editor	White Eastern European	Mild aphasia, walks unaided
Gloria	81	Widowed	1.5	Cleaner	Black Caribbean	Arthritis, asthma, Uses walking stick
Ethel	75	Widowed	3	Cleaner	White British	Arthritis, heart problems, thyroid condition, walking frame
Alfred	84	Widowed	2	Lorry driver	White British	Uses walking stick
Joan	79	Widowed	1.5	Housewife	White British	Diabetes, osteoarthritis, walks short distances unaided
Derek	77	Widowed	1.5	Delivery driver	White British	Diabetes, walks unaided
Sheila	86	Widowed	5	Bookkeeper	White British	Severe arthritis, walks short distances unaided

Self-presentation after stroke

This section examines participants' self-presentation during their narrative interviews following a stroke. Open interviews enabled participants to identify themes that were important to them, as demonstrated by the amount of time spent discussing a topic during the narrative and the prominence participants' gave to topics by bringing them up without prompting. Four main overarching themes were identified: participants' experiences of stroke; work and retirement; bereavement and loneliness; housing and community (see table 2, page 80). The interview, drawing on a biographical-narrative interview method (Rosenthal 2004), began with an open question asking the participants to tell the story of their stroke. The aim was to elicit a detailed narrative indicating how participants made sense of the stroke, what meanings they attached to it, how they presented themselves and how they attempted to locate the stroke in their overall biography. After the initial main narrative, 'internal narrative' questions were asked that elicited more detail regarding themes already discussed by participants, followed up with 'external narrative' questions concerning topics of interest that had not previously been discussed.

Each of the participants' narratives were categorised under one of the four main themes, based on the most salient topic of the narrative (see table 2, page 80). The narratives of only four stroke survivors' (and three spouses) were identified as not having one main theme that emerged as more prominent than others and were categorised under multiple themes (indicated by an asterisk in the table). Although all participants discussed the stroke, some focused on other themes in more detail, or focused on the stroke in relation to another theme such as work or loneliness. Spouses participated

in these narrative themes, with some also talking about their caring role and their own ill health, discussed in more detail in Chapter Five. I now discuss each narrative theme in order of prominence.

Stroke

This section discusses self-presentation in relation to the theme of stroke. This was the focus of the initial interview question, inviting participants to 'tell the story' of their stroke and most focused on this. Fifteen of the 27 stroke survivors spent a greater proportion of the interview talking about their stroke and the impact it had had on their life, compared to other aspects of their biography. Six of these participants had a more severe level of disability as a result of the stroke and used wheelchairs, with the others having a more moderate level of disability.

All of these participants reported experiencing other health conditions. Some had experienced many years of ill health prior to their stroke, which they reported as worsening its impact. Participants' narratives focusing on stroke were therefore often inextricably linked with accounts of other health problems and this contributed to their self-presentation as stoical people, familiar with the hardships of ill health and disability.

Two groups were identified in relation to stroke and self-presentation; 'surviving' and 'positive' and these are now discussed.

Self-presentations as 'surviving'

Five participants (Helen, Grace, Gloria, Paul, Leonard) did not engage in a positive self-presentation because the stroke and other aspects of ill health were the predominant focus of their narrative, reflecting the hardships of their

daily lives. They were all quite disabled after the stroke (three were wheelchair users and two used a stick) and in poor health generally, appearing to be frail and vulnerable; their self-presentation indicated that they appeared to be 'surviving'. With the exception of Helen, all were Black Caribbean, lived in rented council flats and had previously worked in low skilled manual occupations. Gloria, Paul and Leonard lived alone and appeared to be quite socially isolated with very few relatives living nearby.

I now focus on two of these five participants, Helen and Grace, both interviewed with their spouses, as two examples of participants who did not engage in positive self-presentations, but rather as 'surviving'. Although both couples were from very different backgrounds there were common themes in their narratives. Helen and John were white British, owned their own home and consulting business and paid towards Helen's daily care with their savings. Grace and Simon were black Caribbean with Grace previously working as a home carer and John a hospital porter; they lived in a rented council flat. However both Helen and Grace were wheelchair users and talked about suffering ill health and coping with pain. Their husbands were their carers despite having health problems themselves. Their husbands seemed to bolster their accounts, presenting the couples as 'getting on' with life, and perhaps wanting to appear positive for the benefit of their wives.

Helen, aged 84 and her husband John, aged 85, had worked in professional occupations. Helen had her stroke eleven years ago. She had collapsed when she tried to get out of bed and John called an ambulance and she was taken to hospital. After the stroke Helen was paralysed on one side but with the use of two sticks and the help of her husband she managed to walk a bit. However five and half years ago she had to have her leg amputated as she

had gangrene as a result of diabetes. Since then Helen had to rely on help from care workers during the day and the night. She also reported suffering 'phantom' pains regularly when her stump was knocked. John also had health problems, including osteoarthritis and heart problems, and at the time of the interview he had a leg ulcer that had become infected and so he was also using a wheelchair. Up until a few years ago they had been living in their family home in Hertfordshire but had since moved to a flat in London to be closer to their son and his family and to live in accommodation more suitable for Helen. Helen missed their previous home and the friends they had there. She appeared to feel down and John bolstered her account by describing how they had adapted to their health problems and disability, as can be seen in the following quote.

John: I know to outsiders it might seem like we have a lot of problems but you change your habits, you gradually get used to things. (Helen's stroke) happened 11 years ago and your life just evolves. You just get on with it. You take each day as it comes and you acclimatise.

Helen:...I don't know if I'm much support to anyone.

John: Well you can't be physically but you can in other ways.

(John, aged 85, spouse of stroke survivor)

This quote indicates that John is aware that to others who do not know them they appear to both be suffering from a lot of health problems and disability which may evoke sympathy. However his narrative bolstered Helen's account by presenting them as doing their best to 'get on' with life and he talked about their son, daughter-in-law and grandson with whom they enjoyed spending time.

Grace, aged 78, and Simon, aged 75, were from Jamaica and lived in a council flat. They had been married for 20 years and both had children from previous marriages. Grace had her stroke 12 years ago. When she had the stroke she was sitting on the toilet and could not get up so had to phone Simon who was at work. He came home and called an ambulance and she subsequently spent two months in hospital. She used a walking frame to get around the house but used a wheelchair outside although she said she rarely left the house. The council had moved them to more accessible ground floor accommodation since her stroke. Simon was her full time carer although he also had health problems. Grace also had diabetes and talked about suffering much pain, or 'trouble', due to the stroke and arthritis in her hip and shoulder, and said she wanted the 'Lord to take her'.

At night when I lying down and I stretch this (leg) out a lot, stretch it back, I almost want to cry... If the Lord take me it will be better because now I have no trouble. And everyday this trouble trouble. If (God) take me and provide a place for me. Simon I know you don't like what I'm saying....Don't know how long I will be suffering with this...It's the stroke is the pain all over you know... (Simon) have to put my clothes on for me, so it is really bad, really, he wash me, so I am really bad and I'm not hiding it and I can't because God give me him for a reason.

(Grace, aged 78, stroke survivor)

She talked about how grateful she was for her husband's help and said that none of her children would have helped her in the way that he did. Simon appeared to be a little embarrassed when Grace talked about this. He said he had 'prostate problems' but did not talk about this in any more detail and, like John, he did not seem to want to dwell on negative topics and attempted to construct a presentation as a couple getting on with life to the best of their ability.

This group of five 'survivors' were all frail and quite disabled due to the stroke and other chronic conditions, and were dependent on others for daily care. Their narratives largely focused on their poor health and hardships of their daily lives and they appeared to be experiencing some discomfort and pain. These narratives corresponded to 'chaos' narrative types, described as 'anti-narratives' without temporal order, characterised by despair, hopelessness and vulnerability (Frank, (1995). France et al. (2013) found that three of the 18 stroke survivors' in their study displayed narratives that corresponded to the 'chaos' type. In the present study, although the narratives of this group of 'survivors' were not wholly without temporal order, the interviews took less

of a narrative form, with participants giving less detail and requiring more questioning and probing from the interviewer.

It could be argued that this group were experiencing the fourth age as 'a location stripped of the social and cultural capital that is most valued and which allows for the articulation of choice, autonomy, self-expression and pleasure in later life' (Gilleard and Higgs 2010: 123). Although many of the participants displayed characteristics in line with Laslett's (1989) concept of the fourth age as associated with serious illness and physical dependence, Gilleard and Higgs' (2010) altogether bleaker notion of the fourth age as a social and cultural 'black hole' has relevance for this small group of stroke survivors who appeared to have little quality of life and be in greater functional decline in comparison to the other participants.

Positive self-presentations

The other ten stroke survivors (Gretal, Jack, Hilary, Sarah, Ted, Patrick, Molly, Martha, Tony Tom) of the 15 who focused on their stroke during their narrative gave a more positive self-presentation. Compared to the first group, all in this group had a higher level of mobility, apart from Jack and Sarah who used a wheelchair. Despite experiencing the stroke and other adversity in life this group of participants were keen to present themselves as active, engaged and resilient older people who were making the best of their life, distancing themselves from the image of older people as decrepit and dependent. I now focus on Gretal, Jack and Hilary as examples of participants who presented themselves as more positive and stoical.

Gretal, aged 78, had a stroke just over a year ago, 12 days after celebrating her golden wedding anniversary. She woke up and was unable to move her arm. Her husband wanted to call an ambulance but she wanted to see if she would improve so after washing and dressing she called her doctor who called an ambulance for her straight away. She spent the night in hospital on a mixed ward with men and was very upset by this experience. Since the stroke her balance had been affected and she walked with a stick. Although her mobility had also been affected by two previous operations to replace her knee. The first one was four years prior to the interview, which 'went wrong' and led to her being 'very ill' and the other was nine months prior to the interview to correct the first operation. She now had to rely more on her husband as she was unable to do many chores around the house. She felt she had lost her independence since the stroke as she was no longer able to go out alone, and she had previously enjoyed 'window shopping' and spending time with friends but could only now go out with her husband. However she presented herself as a very positive, stoical person who tried her best to be as independent as possible. She felt grateful for the support of her husband and children and grandchildren.

I'm positive. I don't say 'oh poor me', I'm not, always millions of people worse off than I am. That helps. I have a very very supportive husband... (Life) has changed. Mainly because I lost my independence. Whereas before I would go. You know sometimes, I always think it's good for a couple to be away for a few hours because we're both retired and 24 hours a day, the happiest of marriages- we celebrated our Golden wedding. Actually 12 days after our Golden wedding I had the stroke. Whether it was the excitement and everything (laughs) but I doubt it. It was such a happy day. So yes (life) has

changed. My attitude is life as such hasn't changed, I mean I'm still the person I was before, positive thinking.

(Gretal, married, aged 78)

Jack, aged 79, had a stroke just over a year ago when he tried to get out of bed on a Sunday morning and collapsed. His wife called the ambulance and he spent six weeks in hospital. Jack's mobility was limited and he used a walking frame inside and outside of the house but could not walk far outside and was looking to purchase a mobility scooter. Although he could wash and dress himself, he received a lot of practical help from his wife who was his full time carer. Jack had experienced ill health before the stroke. He worked as a foreman for a building firm and eight years ago he had had an accident at work and as a result he had to have his spleen removed which had affected his immune system and so he had to take regular medication. He had also had a hip replacement a few years ago which had meant he was using a stick to walk before the stroke. About a year before the stroke he had been diagnosed with carpal tunnel syndrome in one hand which affected the nerves and so he had limited movement in that hand. He also had high cholesterol for which he was taking medication. Additionally Jack had recently experienced chest problems and was due to have a chest x-ray. Despite being very disabled he presented himself as a stoical person who was 'lucky' to have the support of his sons and to have his wife to look after him.

Jack: We've been getting through things.

Penny: Oh we've had our ups and downs, but we've managed to get through okay,

J. ...I'm very, very lucky I've got her.

P: Well yes, *that's what I say like, you know. We've had our ups and down.*

Hilary, aged 79, had a stroke nearly two and half years ago. She was from a middle class background, unlike the majority of the other participants. She reported that she had been out with her husband Adam to look at venues to celebrate their Golden wedding anniversary. On the way home in the car she became unable to move her arm and had several more incidences at home of feeling something 'going wrong'. Her husband called the ambulance and she was taken to hospital. She had to wait to be seen in the Accident and Emergency department as it was a Friday night and the hospital was 'packed full of drunks and junkies' but she felt the care was good when she was moved up to a ward.

Since the stroke Hilary could no longer walk as far as she used to and found it difficult to walk in a straight line and felt her 'temperament' had changed as she had less patience. She also said she had to rely on her husband more for things, such as help with the weekly supermarket shop. However Hilary presented herself as someone who was independent and in relatively good health and who felt lucky compared to others who had had a worse stroke, including her father.

I'm still inclined to find it very difficult to walk in a straight line but I don't know if that's just old age or what it is (laughs) or if everybody's like that. So you know I've been incredibly, incredibly lucky. And my father was 49 and he had a very tough um, he was in two World Wars, he went in the first one at 17 and he had five strokes and he ended up for 11 years unable to speak properly and unable to move his hand, he could move his legs but he couldn't move

his arms and so um I know how ghastly it can be, you know. So of course that was many years ago now so again that's different. But you still hear of perfectly normal people who have a bad stroke don't you and they have a terrible time so lucky old me (laughs).

(Hilary, married, aged 79)

In Hilary's quote above she engages in downward social comparison (comparisons to other worse-off stroke survivors or various other imagined alternatives) feeling 'incredibly lucky' compared to her father who was far more disabled following his stroke. Downward social comparison was a strategy that a number of participants in this group engaged in during their narratives, as a way to present themselves as positive and resilient. For example the previous quote from Greta says 'always millions of people worse off than I am' as a way of demonstrating a positive outlook rather than feeling 'sorry' for herself. This concurs with findings from a review of qualitative studies on adjustment and resilience after stroke (Sarre et al, 2014) that identifies downward social comparisons as an important strategy in adjusting after stroke, although this is not a strategy reported in the wider literature on resilience.

The narratives of this group of participants correspond to 'quest memoir' illness narrative type, where the illness is incorporated into life, and trials are told stoically (Frank, 1995). France et al (2013) also found that stroke survivors (aged 44-85) presented narratives with quest memoir as the dominant genre, indicating acceptance and adaptation to the effects of stroke, with half of their eighteen participants displaying this narrative type. As in the present study, their participants presenting 'quest memoirs' also commonly referred to feeling lucky compared to other stroke survivors who

were worse off, with some older participants indicating lower health expectations due to age.

Hilary's quote above implies that with 'old age' she expects some physical difficulties and health issues, indicating the importance of health expectations in the experience of chronic illness in older age (Victor, 2005). This was indicated in the narratives of other participants in this group of ten. For example Gretal said she had become more forgetful after the stroke but said 'as one gets older one becomes forgetful'. Martha also said that 'she shouldn't be assuming' a full recovery after the stroke at 'my age'. Drawing on common cultural images of old age associated with declining health and function and discussing old age as a factor in recovery after stroke (and in relation to health more generally) served as a kind of 'justification' for experiencing mental and physical disability following the stroke. Old age was also used as another measure of downward comparison, ie. comparisons to others of a similar age who are in poorer health or had lower levels of physical functioning. Age was also found to be an important narrative resource for older participants (aged 51-91 years) diagnosed with osteoarthritis as they also drew on common cultural images of ageing to present pain and illness as a normal part of old age but were keen to present themselves as independent, and not as a burden to society or their families (Sanders et al., 2002). The present findings also support those of a study on identity in older age among a sample aged 65 years and over with at a mean of five self-reported conditions, where a group who regarded themselves as 'definitely old' underplayed the impact of chronic conditions on everyday life and distanced themselves from other older people as a way of resisting the stigma associated with the social image of old age (Rozario and Derienzis, 2009).

In summary, five stroke survivors did not engage in a positive self-presentation, with the stroke and other aspects of ill health being the predominant focus of their narrative. Helen and Grace's self-presentations were bolstered by their husbands who tried to portray their accounts in a more positive light, which is discussed in more detail in Chapter Five. Although this group of five were quite disabled as a result of the stroke and other health conditions, the differences between these groups could not be explained by level of disability as some participants such as Sarah and Jack were severely disabled since the stroke and used a wheelchair outside their home and a walking frame inside, yet presented themselves in a generally positive way. However the first group seemed to have a poorer quality of life and so appeared to be 'surviving' as they were in poorer health than most of the other participants, based on their accounts of their health and their talk about suffering a certain amount of pain on a regular basis. For this reason their narratives were less detailed and rich than the others and they focused mainly on the stroke, their disability and other health conditions rather than on any other dominant themes, discussed below, such as work and retirement. The self-presentations of participants in this group reflect notions of the 'fourth age', a period of old age characterised by serious illness, functional decline, frailty and physical dependence (Laslett, 1989) and 'as a location stripped of the social and cultural capital that is most valued and which allows for the articulation of choice, autonomy, self-expression and pleasure in later life' (Gilleard and Higgs, 2010: 123).

The other group of ten stroke survivors (and nine spouses) gave a more positive self-presentation. This group displayed elements of a 'salvaged self' (Charmaz, 1987) referring to those who attempt to present themselves to others in a positive light despite the limitations of their illness or attempt to

continue some favoured personal attribute or activity from the past. These participants discussed the negative impact the stroke had had on their life but they all presented themselves as generally positive, stoical people, trying their best to live as independently as possible, supported by previous findings showing the importance of maintaining a positive sense of self and remaining as independent as possible for older people's identity (Tanner 2001). The majority of participants in that study discussed positive aspects of their life that they felt 'lucky' or 'grateful' for, such as having supportive family members and good relationships with children and grandchildren. Similarly, drawing on support from ongoing social relationships and maintaining social roles were strategies that older people, aged 70-80, with more resilient outcomes engaged in when experiencing adversity (Hildon et al 2008). Participants in the present study were keen to present themselves as older people with a positive outlook rather than as 'elderly stroke victims'. Although it cannot be determined whether these ten participants were actually more resilient than the first group of five, what is important here is that they presented themselves in this way.

It is important to note that the presence of spousal carers may have influenced participants' talk about having supportive family members in particular. Spouses also contributed to positive self-presentations which is discussed in more detail in Chapter Five.

After stroke the most salient topic for participants was work and retirement, which is now discussed.

Work and retirement

This theme focuses on the importance of work and retirement in self-presentation. Eight stroke survivors and four spouses drew on their past working lives during their narratives bringing up the topic spontaneously and talking about it at length (see table 2, page 80). Other participants did not discuss work or retirement or mentioned this briefly in passing as their presentation centred on the other main themes. All of the twelve participants had worked in mainly routine manual occupations such as cook, cleaner and factory worker. The significance of paid employment was very important for the identity of both the six women and six men. These participants presented themselves as hard working people with a strong work ethic, and often talked about how they had worked since they were teenagers and how much they now missed working since retiring. They talked about how they valued the social aspect of meeting people at work, the structure it provided to their day and the financial independence it gave them. Narratives about work and employment appeared to serve as a way of presenting themselves as useful, honest and hardworking people, distancing themselves from an identity associated with ill health and old age.

Five participants (Bob, Mary, Tim, Eric/ Irene) talked about work and retirement directly in relation to the stroke, discussed in further detail in the section below on 'stroke as biographical disruption'. This section focuses on the remaining seven participants, (Sheila, Sarah/ Nelson, Patrick / Betty and Ted/ Rita) who discussed their past working lives in general rather than in relation to the stroke.

Sarah (aged 76) and Nelson (aged 77) are from Nigeria and have lived in the UK for 36 years and have four children and grandchildren. Sarah had had her stroke a year ago. She was speaking on the phone to a relative in Nigeria while it had happened. She noticed that her speech was different and her body was weak on one side. Her husband was at home and called the ambulance. She had been in hospital for a few months after the stroke. She was severely disabled and was unable to walk and unable to go out of the house and had help from care workers who came four times a day. She could stand with the help of an electric chair that tilted up and then she could take a few steps using a walking stick. Since the stroke she was unable to go upstairs and so now slept in a hospital bed in the dining room. During their narrative both Sarah and Nelson presented themselves as hard working people, emphasising that they had both worked in the UK since they arrived 36 years ago. Sarah talked about how much she has enjoyed working, distancing herself from those who 'rely on social security money' and 'don't like to work'.

S: I was a cook.

N: For the gas works.

S: And then that closed down I had to go and find another job because I cannot stay home and rely on social security money. I go and find another job at (a laundrette). I was there doing my little bit until I retired...

N: For 21 years.

S: 21 years. And the gas works I was there 15 years... so I worked throughout my life in this country... If not (for) my sickness I don't think I'd stop... I love my job. I don't know why people don't like to work.

(Sarah, stroke survivor, aged 76 and Nelson, husband of stroke survivor, aged 77)

Patrick (aged 85) experienced his stroke at 5am in the morning and he had fallen in the bathroom and his wife, Betty (aged 83), had called an ambulance. The stroke had left him deaf in one ear but he was still able to walk unaided although he could not walk as far since the stroke and was not as active as he had been before. Patrick had worked at the docks as a shipbuilder and then as a van driver for the local council and Betty had worked in a bookmakers but they were now both retired. They did not have children and had no close living relatives. The quote below from the couple shows their presentation as honest, hard-working and moral, with Patrick comparing his state pension with the money 'benefit cheats' receive and Betty drawing on her experience of discovering that her colleagues were defrauding the bookmaking company she had worked for:

P: You'd be surprised what goes on there, benefit cheats isn't it? They're getting all this money, and they're walking about doing work and climbing ladders. And they're walking. All the money they're getting and I'm getting hardly anything.

B:I've got a good reference (from the bookmakers I worked in). It is a lovely reference... The two women, the women that was over me (my managers)...

P: thieving, weren't they?

B: Yes they were thieving of course... (Colleagues) used to laugh at me and I used to say, 'I found this two shillings,' or whatever it was. 'Oh,' they used to say, 'For God's sake, put it in your pocket.' 'No, no, no,' I said, (they said) 'For God's sake, put it in your pocket'... I missed working.

(Patrick, stroke survivor, aged 85 and Betty, aged 83)

Patrick emphasised what a hard worker he had been and was very proud of his 'undisturbed' work record, not ever having arrived late or taken a sick day in the fifteen years he worked for the local council as a van driver. His narrative demonstrates his strong work ethic.

*I used to be a ship builder, a ship repairer...at the *** docks. I used to travel down there to work, and the work come to an end like, you know. So I got a job in the council, *** Council, I was driving a van. I was there, I was there 15 years in ***, driving a van. I wasn't late, I never lost a day's work, I wasn't sick. And they couldn't believe it up there. Me record wasn't disturbed like, you know, with having a week off sick or whatever... They didn't know who I was there, because I was no trouble.*

(Patrick, stroke survivor, aged 85)

Ted (aged 84) and Rita (aged 83) also talked about their past working lives. Two and a half years ago Ted was crossing the street to go to the post office when he collapsed with the stroke and was taken to hospital in an ambulance. He was now able to walk but only short distances, however he also had glaucoma and shortly after his stroke his eyesight had further deteriorated so he was now registered blind. Rita had also experienced much ill health, including a heart condition and severe arthritis. Rita in particular presented herself as hard-working and stoical. Her narrative had a strong moral dimension drawing on her experiences of employment and linking her retirement to her experiences of ill health, as the quote below demonstrates. It also highlights the ways in which many of these older informal carers experienced ill health themselves.

R: I've always had to work hard. I've had to go out early morning cleaning, 5 o'clock in the morning waiting for the old trams years and years ago in the thick snow... and I went to waitressing and then I was cook... I wish I could go back to work, wish I could have them days back to work again. Because once you retire you get everything happen, you know, everything (in your body) goes... I was right as rain while I was working...I mean it's like TB, when they said I had TB. They cured that but it's come back again.

T: You never had TB.

R: No I just said to the girl I didn't have TB.

T: They thought you had TB.

R: They thought I had TB....I've had that removed, gall bladder removed, I've had ulcer, I've had hernia, peritonitis, gangrene in the intestines...

T: They never had the antibiotics they got now.

R: Hang on (to husband)... So (I've) been through the wars and all through this World War and all, picked up out of the rubble, still going on (laughs)... I've been in and out of hospital more times than hot dinner (laughs).

(Ted, stroke survivor, aged 84 and Rita, aged 83)

Sheila's narrative would often stray from the topic of her stroke and focused mainly on her past working life, giving many little anecdotes. She was a widow and lived alone in sheltered housing and presented herself as a hard-working, independent and well-travelled woman. She appeared to have led a very interesting and unconventional life, distancing herself from some of her female peers who she regarded as being content to settle down, marry and have children. She had worked for the majority of her life and travelled a great deal. She talked about working as a Land Girl on a farm on the Isle of Wight during the Second World War and how different it was compared to her upbringing in South-East London. She had thoroughly enjoyed this

experience, although she said that working with heavy farm machinery had led to severe arthritis in later life, mainly in her back. After the War she then travelled to Australia where she worked for a few years as a bookkeeper. She talked about how much she had enjoyed this experience and how 'useful' she had been as a worker there. Six years later she returned to the UK and was employed in various occupations including bar maid and bookkeeper.

Travel was all I wanted. At that time, they brought in a new regulation, you could emigrate to Australia for ten pounds. I thought, 'Oh lovely, I'll travel. And it will only cost me ten pounds.' Which I did do. Well I spent six years there...the first part I was in Brisbane, and when I went next time, I was in Perth, Western Australia, because you always travel there by sea, you didn't fly in those days. And I worked there, mostly office work, because you see, when I was at school, I trained as a bookkeeper, and I did such a thorough job, I could more or less tackle anything afterwards, you know, bookkeeping. And that's what I did, I got a job as a bookkeeper, and, of course, they hadn't had the standard of education there, so I was jolly useful, you know, for a big company. That was another thing! The things I got up to was nobody's business.

(Sheila, widowed, aged 86)

Sheila had got married later in life to a widower with ten children but had not been able to have children of her own. She presented herself as someone who was always involved in local politics throughout her life and she reported being elected as a local councillor three times during her 70s. She spoke of this with pride, particularly the fact that she had retired at the age of 78 despite the official retirement age of 65.

*I've always been a Liberal Democrat... I did alright, I was elected three times. I was living in *** Road at that time, and it was '94, '98 and 2002. Yes, yes 2002 I was 78. And I wouldn't admit it, I wouldn't tell them, I wouldn't retire because I was over 65. So I just continued working as a councillor, as I said, until 2002. And that's when I resigned. 2002. Well I was 78 and everybody else was retiring at 65. So I thought I'd leave room for everybody else.*
(Sheila, widowed, aged 86)

These examples illustrate the ways in which these participants' narratives portrayed the period in their life while they were working as the 'good old days', before they had developed any serious health problems and were 'as right as rain' (Rita). Their narratives evoked fond memories of their working days, despite working in low paid, low status jobs that were often physically demanding. Through their narratives about working these participants presented themselves as useful, honest and hardworking people, distancing themselves from the negative connotations associated with stroke, and ill health and old age more generally. Paid employment was very important for these participants' identity and is associated with a strong work ethic and a resistance to dependence on state welfare. By emphasising how hard-working, honest and self-sufficient they were participants are resisting the image of old age as associated with 'dependency and uselessness' (Wang, 1999). Participants also disassociated themselves from dependence on state welfare and from 'benefit cheats' by establishing their self-worth as hard workers.

The importance of work for identity in older age are supported by findings that older residents living in sheltered accommodation, mainly from middle class backgrounds, displayed a denial of old age and distanced themselves from

the stigma of old age through attempting to reconstruct past identities and roles, often associated with previous employment, reproducing status hierarchy (Gamliel and Hazan, 2006). However participants in the current study, who drew on their past employment as a dominant theme in their self-presentation, were all from working class backgrounds, having previously worked in mainly routine manual occupations and were not presenting their previous work roles in relation to status. In fact the opposite appeared to be true, for example Patrick stated that his employers 'didn't know who I was there, because I was no trouble' as a way to emphasise his 15 years of service as a van driver for the local council without a single sick day. Therefore it is not the nature or the status of the work that appeared to be of particular importance in self-presentation but it is the self-presentation as hardworking, honest and financially self-sufficient people.

It was notable that whereas participants working in routine occupations drew on past identities linked to employment in their self-presentation, those participants working in managerial and professional occupations spent very little time talking about previous employment roles in their self-presentation. These findings relate to the structure of moral belief identified in relation to the 'capitalist work ethic' that underpinned attitudes towards work and accounts of work of participants from East London, informing their approach to health and illness (Cornwell, 1984). Even when a person was ill or retired it was important for them and others to 'establish their credentials as (previously) good workers and as people who have never not been willing to work' (1984: 71). The current findings indicate that for some participants from working class backgrounds the importance of establishing credentials as previously good workers continues well after retirement, into old age. This possibly becomes even more salient in old age when older people may be

more likely to experience insecurity and uncertainty about their role in a capitalist society where identities are strongly linked to the roles of producer and consumer (Phillipson, 1998). It is also perhaps more salient for those who had previously worked in lower paid jobs who are more likely to experience a lack of financial security in old age compared to those who had been employed in higher paid jobs.

The next section examines participant's self-presentation in relation to the third most common theme of loneliness and bereavement.

Loneliness and bereavement

For six participants loneliness was a dominant theme throughout their narrative. Loneliness is regarded as a personal, subjective experience, as distinguished from social isolation which refers to an objective measure (Jylhä and Saarenheimo 2010). Five stroke survivors talked about the death of a close family member and how they felt lonely as a result. Some described themselves as feeling 'lonely' and others strongly implied it when talking about how much they missed their loved ones who had died. These experiences are in line with what has been termed 'emotional loneliness' which comes from an absence of a reliable attachment figure and lack of intimate relations, as opposed to 'social loneliness' which refers to an absence of a broad social network or recognised social roles (Weiss 1973). The narratives of this group of stroke survivors mainly focused on bereavement and the subsequent emotional loneliness they were experiencing.

One participant, Delia (aged 75), reported that her feelings of loneliness were due to not having a partner as she was divorced. Her narrative is discussed in more detail in the section below on stroke as biographical disruption (page 131). The other five stroke survivors discussed the death of a close relative. For three this was the death of their spouse, for another the death of his wife and son and another talked about the death of her daughter. These participants presented themselves as people to whom family was very important and as people who were trying to make the best of life, despite experiencing loneliness after the death of a loved one. I now examine each of these five participants' narratives in turn.

Sheila (aged 86), discussed above, was an 86 year old widow who lived in sheltered accommodation, with limited mobility due to the stroke and severe arthritis. She had previously been a very independent person and, as mentioned, she had been in the Women's Land Army during the Second World War and then lived in Australia for six years when she was younger and had worked as a bookkeeper. She did not have any children but her husband was a widower who had ten children. She said she was close to her daughter-in-law (who had been married to one of her husband's sons) who was also a widow. She talked about the traumatic experience of her husband drowning after an accident at work. Although this happened 27 years ago she describes it as 'a more worrying time than the stroke' and implies that this experience and others (including her severe arthritis) had led her to experience the stroke as another hardship in life that she 'got on with'.

(My husband) was a docker and he was drowned in the Thames over an accident when they were dealing with one of the boats...he floated backwards and forwards for days before they could get his body out of the river. So he

was in a dreadful state, so they wouldn't allow me to see him, they just put him straight in the coffin and that was it... That was a more worrying time than the stroke. So I was at the stage then, when I had the stroke, that I was used to more serious injuries, being in contact with them and everything else. I didn't cry me eyes out, you know, I just sort of got on with it.

(Sheila, widowed, aged 86)

Derek (aged 77) was a widower who lived alone in a council flat. When he had the stroke five years ago he was shopping in a supermarket and picked up a jar and dropped it because he could not grip it as his arm and hand were partially paralysed. He already had an appointment with his GP in the afternoon so when he told his GP he was sent straight to hospital. He had largely recovered physically from the stroke and was able to walk and drive but described feeling very emotional since his stroke. He also had diabetes and respiratory problems. One of the main themes of his narrative was his wife's death and he seemed to be very lonely and quite socially isolated with no friends or relatives living nearby, although he saw his daughter and granddaughter quite regularly even though they lived two hours drive away. He had many photos of his wife up around his living room. His experience of caring for his wife at home while she was ill and her subsequent death ten years ago was presented as more of a disruption to his life than his stroke five years ago. His wife had emphysema and he stopped working to care for her for five years before she died. He talked about her suffering and described feeling 'useless' when he felt unable to help her.

(We were married) 43 years... (My wife died) going on ten years, yes (on) St Valentine's bloody day... the bit that annoys me more than anything is people treat you like an idiot. Not intentionally, but they talk to me, but they won't

talk about (my wife). It's as if they're trying to say she never existed. I know bloody well she did. And that annoys me... (When my wife died of emphysema, she was desperate, really was. She would sit here and she would put two words together and she would be going (laboured breathing sounds). That is the bit that got me more than anything. There's nothing you can do, you feel like, you know, I don't know, you feel like strangling yourself, you're so bloody useless... We had a good life, we both enjoyed ourselves. Didn't do a lot but we enjoyed ourselves. She was happy with me and I was happy with her.

(Derek, Widower, aged 77)

Joan (aged 79) was a widow who lived alone in a council flat. Nearly two years ago Joan had been admitted to hospital as she was unwell and the day after she was admitted she had the stroke. She gradually regained her speech and physical ability but she could not walk far after the stroke and used a stick. For her the relatively recent death of her husband a year ago had also been experienced as more of a disruption to life than her stroke. Three months after her stroke her husband had become ill with a heart condition and despite having difficulty getting around after the stroke she had cared for him at home for six months before he died. Although she had three children (one daughter lived abroad) and grandchildren she said she did not see them that often and felt very lonely. She presented herself as trying her best to get on with life without her husband, describing herself as a 'fighter'. She said she knew she had to get used to the loneliness but it was 'eating away at her' and that she felt 'left behind' after her husband's death.

When my husband was alive, it was alright, but now I want to talk to somebody and there's no one here, and I turn to him to tell him something

and he's not here... When you're from a big family and then you've got absolutely no one, it's, it's frightening, you know. And so I always had a big family, six girls and two boys we were, you know. And now I just can't get, couldn't get used to the idea of being alone. I've turned round to talk to someone, there was no one here. You know, it's a terrible, terrible feeling, you know. That's why I said when Jesus takes us, he should take both the parties, you know. Not leave one behind... But the loneliness is, it eats away at you, you know, it's terribly upsetting and things like that. And I never go out on my own, that is why I don't know a lot of the places, you know, to go, everything looks the same to me. And my husband used to have a car, so he used to take me all over, you know. But when he got ill and things like that, he gave up the car.

(Joan, aged 79, widowed)

As well as experiencing emotional loneliness, Joan was also experiencing a certain level of social loneliness since her husband died as her social life seemed to be very much linked with her husband's, particularly as he used to drive the two of them around and as Joan did not drive she no longer had this freedom. She did see some of her children and grandchildren quite regularly, although she felt that her children did not visit her as often as they had done when her husband was alive. One of her daughters wanted her to move to sheltered accommodation nearer her house in another county outside London, but Joan wanted to stay in the maisonette she had lived in for 30 years, despite experiencing much difficulty using the stairs, as she had lived in the same area for all of her married life, had friends living nearby (although she did not see them that often), went to the local church every Sunday and her doctor's surgery was next door to her block of flats.

Alfred (aged 84) was a widower who lived alone in a council flat. He had four daughters and grandchildren and great grandchildren who lived nearby. He saw them regularly and described having a good relationship with them. He had had a stroke two years ago and now had limited mobility but was still able to go out using a walking frame. When he first came out of hospital he had received physiotherapy and help from paid carers for a few weeks but his wife had been his sole carer. However his wife had died a year ago. His son, to whom he was very close, had also died in a road accident ten years ago which had had a great impact on his life. Although he was trying to carry on with his life after his stroke, for example by going out for a walk every day to get a newspaper and engaging in his hobbies of painting and making model aircraft, he talked about how much he missed his wife and son.

I had four daughters and a son but I lost him in a road accident. That's my son, up there look (pointing to a photo). He was my right hand man. I miss him terribly you know, just as much as you miss your wife. We used to do everything together. But since he died and that's nearly ten years ago now my soul, my heart went out of everything I do.

(Alfred, widowed, aged 84)

Rose (aged 84) was a widow who lived alone in a council flat. She had the stroke 18 months ago in the middle of the night after she went to the bathroom and then collapsed by her bed as her left side was paralysed. Her two daughters were staying with her at the time and she called for them and they called an ambulance. She had received thrombolysis treatment (clot busting drugs) in hospital which she described as 'a miracle', as she felt she had largely recovered from the stroke as a result, although she felt more tired. She had a son and two daughters and grandchildren, some of whom lived

nearby. She had had a third daughter but she had died after a short illness and Rose had experienced this as far more of biographical disruption than her stroke. Her daughter had died a week before her stroke and she felt that the stroke had been caused by the shock of the experience, as she described below.

My daughter had only died the week before (my stroke). She'd been ill for some months but I didn't think we'd lose her then. But, so it wasn't a happy time. I think really what caused the stroke was the shock I had when I went to see her at the chapel of rest, I shouldn't have gone but um I felt I had to. That was such a shock.

(Rose, widowed, aged 84)

For these participants stroke was less significant in their narrative, as their experience of bereavement and loneliness seemed to overshadow their experience of stroke. Overall, these participants' narratives had a real sense of sadness about them. All described the death of their loved one as a 'shock', as they had either died unexpectedly in an accident (Sheila's husband, Alfred's son) or they had suffered from an illness for a period of time before they died (Rose's daughter, Derek's wife, Joan's husband). Derek and Joan in particular talked about the experience of nursing their dying spouses and Derek talked about how traumatic this had been and the memories of her dying still seemed to be very much in his mind even though his wife had died ten years ago. Loneliness was experienced as major consequence of losing a loved one, for example, Joan's vivid description of the loneliness 'eating away at her' and the 'frightening' feeling of 'having absolutely no one' indicate that this was a major life event. All five of these stroke survivors described having regular contact with family members,

mainly children and grandchildren, but still felt lonely. This supports findings that one can feel lonely even in the presence of others (Townsend 1968, Victor, Scambler et al. 2000) and that the quantity of social contacts is less important than the extent to which they meet one's hopes and expectations (Pinquart and Sorensen 2001).

The present findings build on those demonstrating that stroke was experienced as a 'normal crisis' for working class stroke survivors living in the East End (aged 40-87) due to previous experiences of crisis and hardship and familiarity with the worlds of pain, suffering and death (Pound et al. 1998). The current findings provide a specific focus on the experience of bereavement for those of advanced older age, showing that for a particular group of participants it was this experience that was presented as a biographical disruption rather than the stroke which appeared to be experienced more as a 'normal crisis'. Although Bury's (1982) seminal notion of biographical disruption has been used mainly in relation to the experience of chronic illness, the way in which this group of participants presented their experience of bereavement and loneliness indicated that this had been experienced as a biographical disruption leading to overwhelming and dominating uncertainties. Although for some of these participants their loved ones had died quite a few years ago, it seemed to be the impact the loss had had on their life and identity that was important rather than the length of time since the bereavement.

Findings relate to an interview study on the construction of age identity by participants aged 65 and over with at least one chronic condition that identified three categories of age identities: definitely old; definitely not old; and ambivalent about age (Rozario and Derienzis 2009). Those identifying

as 'definitely old' had experienced disabling chronic conditions and the death of a significant other and therefore experienced age as a 'discontinuation' of their middle age. I argue that this 'discontinuation' appears to be in line with notions of biographical disruption. In the current study, the group of participants who presented bereavement as a dominant theme, experienced the death of a loved one as a 'discontinuation' or biographical disruption. This implies that the age identity of these participants may correspond to the category of 'definitely old', demonstrating the significance of Rozario and Derienzis (2009) findings for those aged 75 and over, in advanced older age.

The death of a spouse in particular can result in the highest level of life change, as identified by Elder and Rockwell (1979) in their seminal study of the life-course. In the well-known Social Readjustment Rating Scale the death of a spouse has been rated as requiring the highest level of adjustment that provides a standardized measure of the impact of a wide range of common life events (Holmes and Rahe 1967). More recent research has shown a consistent link between widowhood and the experiences of loneliness and social isolation (Victor, Scambler et al. 2000, Savikko, Routasalo et al. 2005). For those participants whose daily routines are more fixed around their spouses the structure of their life was more altered after the death of a spouse (Hildon et al., 2008). It may be that for Sheila, Derek, Alfred and Joan whose spouses had died, daily routines had been more structured around them. However for other participants (Mary, Bob, Martha, Gloria, Ethel) who had also experienced the death of a spouse within the last few years the experience of bereavement was not a prominent theme in their narrative and so perhaps their routines had been less fixed around their spouses or they had close relationships with other family and friends, mediating the impact of the loss. It may be that these participants had been

able to engage in narrative reconstruction after experiencing biographical disruption caused by the death of a spouse, or other themes had been more salient for their self-presentation at the time of the interview, such as the stroke or housing issues.

It is important to acknowledge that for this group of five participants who had experienced the death of a loved one as a biographical disruption, their stroke appeared to be less severe in comparison to some other participants. Although these participants reported being affected by the stroke, their mobility was less affected and all of them could for walk short distances unaided apart from Alfred who was able to walk with a stick. Therefore had any of these participants experienced a more severe stroke, this may have featured more prominently in their narrative and perhaps may have been experienced as more of a biographical disruption.

Having examined the dominant theme of loneliness and bereavement I now focus on the next most prominent theme of housing and community relating to participants' local, social and physical environments.

Housing and Community

For seven participants (one individual stroke survivors and three couples) their narratives indicated that housing and community were important themes in their narratives. For some participants their discussion of housing was directly linked to the experience of stroke but for others their discussion of housing and community issues provided a wider context for their experiences of stroke in older age and presentation of self.

These seven participants presented themselves as 'good citizens', who cared about their neighbours, their neighbourhood and their local community. They had lived in the same area and in the same home on the same estate for the majority of their lives. They talked about moving into their flats when they were first built in the 1960s and how clean and modern they were. They presented themselves as people who, during their lifetime, had participated in their local community, had developed good relationships with their neighbours and contributed to making their neighbourhood a clean and tidy place to live in. However there was an overall sense that participants had experienced a lot of change in their local neighbourhoods over their lifetime. They talked about the decline in standards of their local environment that they had witnessed over the years, a lack of a sense of local community, and general social problems in relation to their neighbourhood such as anti-social behaviour and crime. They felt other people did not seem to care as much about their living environment or about helping one another, they talked about not knowing their neighbours now whereas previously they would have known everyone in the community. Some participants talked about the great friends they had made in neighbouring flats but how most of them had now died.

This section discusses these participants' self-presentation in relation to issues with the local neighbourhood and then more specifically, issues with housing and related financial problems before the issues are brought together in an overall discussion of housing and community.

Ted (aged 84, stroke survivor) and his wife Rita (aged 83) discussed the social problems they had experienced on the estate they lived on and how much the neighbourhood had changed since they moved in nearly 50 years

ago when the flats were first built. They presented themselves as responsible citizens and good neighbours, who had always contributed to making their neighbourhood a nice and clean place to live and had developed good relationships with their neighbours over the years.

T: 1962 we moved here. It was a new block of flats there.

R: Yeah we moved in to a new block of flats. (Our neighbours and us) all moved in together with our children. The children have all grown up and got married and had children of their own but (our neighbours) have all gone, they've all died off. There's only 3 of us left, from the old, originally... Beautiful block of flats this was, beautiful, clean and everything. It's only what the people they put in, it's only what it can be. They put people in and they don't look after the place. I mean I used to always clean outside of here and clean the stairs and everything but I can't do it now. And we've got a cleaner but he doesn't do it....Times I've been on to the council about it. I mean who wants to get into a dirty lift with shopping and everything. You can't put your shopping down but you can't stand and hold your shopping but they don't do nothing about it, nothing at all do they.

T: Trouble is there's a children's play pen round there (underneath our flat)

R: It's only for the babies.

T: The big boys are in there with their footballs playing there and all. But they play down there and kids and everything use it.

R: ...Them little children who goes in there, they can't go in it 'cause their kicking a ball about. You tell 'em and you get all the abuse so best to keep your mouth shut. You get all the abuse under the sun, don't you. And they don't live here that's the trouble. Times I've phoned the police up on a Sunday afternoon... But the thing is at our age, who wants to uproot.

(Ted, stroke survivor, aged 84 and Rita, aged 83)

Ted and Rita talked about how their estate had changed and how the neighbours that they had made good friends with and with whom they had brought up the families, had all died or moved away. They said that their current neighbours, some of whom were students, did not care about the communal living environment. They told a story about how a garden chair, a cherished family gift, had been stolen for 'drugs money' from the front of their flat despite being securely chained to the wall, illustrating the deterioration of their neighbourhood and the increase in local crime. They talked about how their son had tried to encourage them to move to Devon where he lived but they felt they were too old to 'uproot'.

Ethel (aged 75) also talked about the anti-social behaviour she had experienced on her estate and also the severe financial problems she was experiencing due to her housing. Ethel talked at great length about her extensive housing issues that were a result of purchasing her council flat under Margaret Thatcher's 'Right to Buy' scheme during the 1980s. This appeared to have much more of an effect on her life in comparison to her stroke. Ethel was a widow and lived alone. She had a walking stick but said she preferred to walk outside using a pram as she said she had been used to pushing her children and grandchildren in a pram. However the day centre would not allow her to bring her pram there so she had to use her stick. She also had arthritis, heart problems, high blood pressure and a thyroid condition. Her flat appeared to be unclean and very untidy with piles of papers everywhere. She had no central heating, no hot water and electricity sockets were coming off the wall. In her bathroom upstairs the plug hole in the sink and the bath had become blocked and she had to wash in the bath using water boiled from the kettle in a bowl and then scoop out the water

after. She had had a stroke three years previously while she had been hanging out washing in the back garden and a neighbour who lived in a flat above her saw her collapse and called the emergency services and the police had to break her door down so ambulance staff could get in. Ethel questioned whether she had actually experienced a stroke as she felt the symptoms were more likely to be due to all of the strain she had been under before her stroke. Ethel was outspoken and gave a long, detailed and frank account of the housing and social problems she had experienced over the last few years. She talked about the frequent harassment she had experienced from local youths and how they would throw stones and bricks at her windows and patio doors. She felt that they were targeting her because she was an 'old person'. This situation had become particularly bad during the three week period that her husband was dying at home due to 'diabetes' and an 'enlarged heart'. This harassment continued for a week or two after her husband died. She called the police several times but said they did not stop the problem. She told her daughter about the situation and she knew the boys who were harassing her because they went to the same local school as her children. Ethel reported that her daughter went to talk to two of the mothers of the boys but they attacked her and stole the keys to her son-in-law's van. She said the police then charged her son-in-law. It was shortly after this that she had a stroke.

Night after night (kids) throwing stones at that window... even when my husband was sitting – not in that chair – there was another chair there, sitting there dying for three weeks because he couldn't get up and move – diabetic, enlarged heart, he had it all – the kids were smashing me windows. Night after night I called the police... Now, you read in the paper, everyone picks on the old people for some reason or another. Way of life, I suppose. So

*the week after he died or a couple of weeks, we was arranging his funeral, the kids were still on there. What do I do? I'm sitting here on me own – bang, bang, crash, oh, oh, oh, don't go out, don't face them, don't do anything. I said, 'I'm going to sit here?' Anyway, this night, before the funeral, look out there, there's a pram shed out there, and they was always on that roof throwing stones... So I had to phone me daughter up this night, I said 'They're out there, they're out there.'... She runs up there, or goes up there in the van. Two of the mothers come out, 'My boy's an angel, my boy don't do that.' They ripped lumps of me daughter's ear out, punched her in the face... One of the mums grabbed the keys of me son in law's van. The police were called and my son in law was charged! (laughs) Joke.... It was after then I had the bloody stroke. They call it stroke. So, such is that now, I've been dumped, absolutely, positively dumped.... Ahhh, what do you do? Put up with it, put up with **** Council, put up with the government, put up with society. Look on the bright side and they make you live longer! Why? What for?*
(Ethel, widow, aged 75)

Since her husband died she reported receiving large bills for thousands of pounds from the council for replacement doors and windows and other work to communal areas in the block of flats such as rewiring. She had paid some of this but was unable to pay in full and this meant she could not afford to pay for essential repairs to her central heating, electricity sockets, washing machine and oven, and was unable to repair the blocked plug holes in her sink and bath. She was very angry about this and it was this issue and the harassment by the local youths that dominated her account of her stroke.

£19,000 (the council) want, £19,000 they want. The pressure I live under for nothing. I'm being forced to pay. They want it – 'We'll have a little bit here,

we'll have a little bit there and you can pay so much this month, next month and every other bloody month.' I've paid two lots. It's over £9000 I've paid. And I'm still living – no central heating, no kitchen, no electrics, well that's just there. Washing machine don't work, the oven don't work, the bath don't run away. Modern, civilised country?... (The central heating) wants seeing to, but of course everything that wants seeing to, you've got to pay a £100 before they even come out and look at you. Sod it. I'll live – my generation grew up without technology, without central heating, without constant hot water. I'll survive, bastards. The anger will make me survive.

(Ethel, widow, aged 75)

Ethel presents herself as an 'underdog' coping with anti-social behaviour and unfair financial hardship, doing her best to battle an unjust system that has worked against her. During her narrative she talked about the council, the police and social services all treating her unfairly and not giving her the help she needed and she was very angry about this. She was keen to present herself to professionals from these organisations as a woman willing to stand up for herself, as a stoic 'survivor' brought up in a generation which has withstood hardships, rather than as a victim.

Like Ethel, Patrick (aged 85, stroke survivor) and Betty (aged 83) were also experiencing housing problems as a result of buying their bungalow under the 'Right to Buy' scheme in 1989. In the last part of their narrative they talked about the problems they had had with being charged much more for their heating than their neighbours who were council tenants and they could not afford to pay their large heating bills.

P: And what do you think our (heating) bill is? £783.12 for all our neighbours.... Ours is £1072.01. That's what they're trying to get off us. That's what, nearly £500 more.

B:...I get worked up over it, you know, I go mad really don't I?

P: If we paid what (council tenants) pay, you see what I mean, they stick 10% on top of that for us.

B: We have to pay that extra and all.

P: That would come to £861.43. That's an administration fee. Administration I don't mind paying that, but not £1000 and odd.

(Patrick, stroke survivor, aged 85 and Betty, aged 83)

Patrick and Betty also talked about another charge that the council was bringing back in for freehold owners to cover maintenance of the communal areas which they had not previously paid as they were freehold owners of their property and not leasehold. They felt both of these charges were unfair and were worried about the situation. When they had tried to seek help from the local council and then the Citizens Advice Bureau they had been told that because they were freehold owners they were not entitled to any assistance. This problem appeared to be causing them both quite a lot of anxiety particularly as they presented themselves as 'very honest' people 'who do not owe a penny to anybody' (Patrick). They had an appointment to see someone from a housing charity later that day who they were hoping could be of some assistance.

The self-presentations of Ethel, Patrick and Betty, and Ted and Rita had focused on problems with their housing and their local neighbourhood and the impact that this had had on their daily lives, financially, socially and psychologically indicating that the stroke had been presented as less of a

biographical disruption, discussed further at the end of this section (page 137). For another couple their housing issues were as a direct result of the husbands' stroke and other health conditions, and we now turn to a discussion of their narrative.

The narrative of Richard (aged 83) and his wife Judy (aged 68) was dominated by their housing problems experienced as a result of Richard's stroke. Prior to the stroke Richard had asthma, joint problems and a hereditary sight condition which meant he was registered blind. Richard had had his stroke three years ago after he came back from the pub in the afternoon. He had trouble walking and collapsed in a chair and his wife, Judy, called the doctor. The doctor came to their home and diagnosed a stroke and said she would call an ambulance. However the ambulance did not arrive until hours later. Judy phoned the surgery to see what had happened and was told that the doctor had said it was not an emergency which made Judy 'furious'. Richard was in hospital for ten days. After the stroke he had difficulty walking and a year after this he was diagnosed with diabetes and emphysema which had limited his mobility even further so he now used a wheelchair when he was able to get outside. His wife was his full time carer who washed, dressed him and fed him.

They lived in a high rise council flat on the 11th floor with lifts that were often out of order which meant they were unable to leave the flat. They had been on a list to move to more suitable accommodation for some time and felt 'angry' that nothing was being done to try to move them. In addition, Richard could not get into the bath so Judy struggled to wash him but the council would not fit a shower as they were on a list to move. Judy also talked about the level of crime in the local area and said their next door neighbour was

recently robbed of her pension by men who posed as policeman. Judy presented herself and her husband as moral people with a genuine entitlement to more suitable council housing with better disabled access.

So we're just waiting now just to move. You know, but erm, it seems an ongoing thing forever and ever. I mean, as I said, (Richard's) nephew sent (the council) a fax a few weeks ago and still nothing is happening. So they're just ignoring us, and yet you know, like Deborah Brown (local MP), she didn't do anything. And she wants her votes... I tried to phone her and her secretary said that – I phoned the Houses of Parliament, I got two letters from the Houses of Parliament there. Erm, she said, 'I'll get Deborah Brown (local MP) to phone you,' and she never phoned me. I've got a councillor, Lyn Yates* she contacts me, you know, we sort of speak to one another quite often. And she said, 'Do you want Deborah Brown's phone number?' And I said, 'No, I've got it.' I said, 'It's pointless Lyn.' We're not getting no, you know, no answers from her'. And I said, you know, 'What's annoying Lyn, you know, I'm not ribbing you because you're a Labour person, but they want our votes, and yet they're not prepared to do anything for us.' And she said, 'Yes, I do see.' But she's marvellous, Lyn. Every time, when I told her about Richard being lifted downstairs, straightaway she got on to the lift people... And it's only since he had his stroke that we realised that we just can't live here anymore. It's too high up and we can't rely on the lifts. I mean we've had to walk the stairs many a time before he had the stroke, and it crucified us walking up the – all those flights. So, you know, and no way we could do it now. So we'd been stuck in... And my legs, because I've got poor circulation, because I was under (hospital X) for my diabetes, erm, my legs felt as if they were going to buckle underneath me, walking up the stairs. I've got health problems.*

(Judy, aged 68, spouse of stroke survivor)

**All names have been anonymised*

Judy had had a recent application to claim Carer's Attendance Allowance rejected and someone from Age Concern had been helping her to appeal this decision. Judy was keen to emphasise that it was not the money that was her motivation for appealing but the moral principal that she was entitled to receive the benefit as she was saving the government 'loads of money' through her role as Richard's 'nurse'.

Trish at Age Concern, she's marvellous. She got the Attendance Allowance for us and everything. They turned me down, believe it or not... Yes and she appealed against it... They said, you know, 'Not enough evidence.' I told them what I have to do. She filled in the form and she said, 'This lady has to do – just think what your, you know,' she said, 'The government, she's saving the government loads of money.' She said, 'And you're turning her down?'... she said 'They're not going to get away with that.' She said, because she said, 'You're like his nurse, and you have to do everything for him.' So she's appealed against it, so I'm just waiting for the appeal. But it's going to get £70 for Attendance Allowance. So, it's not the money, I didn't want the money, but she said, you know, 'Mrs Finch you should be getting help, because you do everything for Richard.' She said, 'You know, you have to wash his bottom, everything,' she said, 'And they're getting away with it.' I said, well, you know, I wasn't bothered, it's only because she pushed it because, you know, we live quite comfortable and I thought money didn't bother me. It's never been like that with me, money. You know, we've never gone without. But, you know, she said, 'No, you're not going to live like that,

because he needs, you need some help because of what you're doing for Richard.'

(Judy, aged 68, spouse of stroke survivor)

Like Ethel, Judy also presented herself as someone battling against an unjust system. Her narrative discussing her good relationships with her local councillor and the professional from Age Concern and all the help and support they have given them, lent support to their presentation as a deserving couple with a legitimate claim to suitable housing and financial assistance from the government. Judy is also keen to present herself to these professionals as a moral and honest person, distancing herself from others who have to rely on benefits.

Although none of the participants from middle class backgrounds talked about housing and community as a main theme in their narrative, one of these couples, Helen and John, discussed having to move after Helen had the stroke ten years ago. They had to sell their family home in a home county outside of London that they had lived in for 46 years as it became unsuitable for Helen's needs as a wheelchair user, so they bought a flat in London to be near their son and his family. Like the other participants who discussed housing and community they also said that many of their old neighbours had either moved or died. However unlike Richard and Judy, Helen and John had the financial resources to enable them to move to a property that could meet Helen's needs and be closer to their family. They noted that one of the advantages of living in their flat was that the lifts worked and that if one was out of order the other one would still work. Their experience contrasts with Richard and Judy's experience, illustrating the importance of financial resources in influencing participants' narratives of living with stroke.

However, although John and Helen had greater financial resources they implied that this had actually not been an advantage in terms of paying for Helen's care. They stated that 'our bank manager says we made a mistake by saving so much' (John) 'because social services took it all to pay for my care' (Helen).

Housing and community: discussion

For Ted and Rita and Patrick and Betty the stroke was a joint dominant theme in their self-presentation together with housing and community issues. For Ethel, housing and community issues were the main focus of her narrative and for Richard and Judy their discussion of housing was closely linked with Richard's stroke and other health problems.

Ethel, Patrick and Betty, and Richard and Judy's narratives had focused on their housing problems and the impact that this had had on their daily lives, financially, socially and psychologically. Therefore the stroke had been presented as less of a biographical disruption because at the time of the interviews these on-going problems were more prominent in their lives. This was mainly due to the financial impact, particularly for Ethel who was living in very poor housing conditions without heating, electricity, hot water, a washing machine or oven. Richard and Judy's housing issues were as a result of Richard's stroke and other health conditions, particularly his emphysema and very limited eyesight, but also Judy's poor health as she had diabetes and poor circulation; this meant their high rise flat was unsuitable with poor access and no shower. The quality of life of these participants had all been affected by the issues with their housing and local environment. All of these participants talked about how they had asked for assistance from certain

authorities, such as the Police and the Council, but they felt that they had not been listened to and not received the help they needed which frustrated and upset them.

All of the participants who focused on housing and community as a dominant theme of self-presentation lived on council housing estates and had lived there for the majority of their lives. Ethel, Richard and Judy and Patrick and Betty all discussed their experiences of crime and anti-social behaviour in their local estates which reflected a wider theme of community, in particular the changes in the nature of their local community that they had experienced over their lifetime. In their classic study of social life among an urban working class community in Bethnal Green, Willmott, Young et al. (1957) gave a detailed account of community life and social relationships for East Enders living in the new estates built to rehouse people as a result of the slum clearance after the Second World War. By community they referred to collective life and social relationships centred on reputation rather than status or money. Cornwell (1984), writing nearly thirty years later in her study of family and social life in the same area, criticised Willmott and Young (1957) for romanticising the notion of community. She argued that the pre-war pattern of social life was already disappearing and the urban village community they described was an image gaining in significance because of the threat of rapid social changes already under way. In her study of life in the East End she found that participants portrayed romanticised past images and experiences of community in their 'public accounts'. They talked about the sense of community and the shared experience of poverty in the tenements they were housed in before the Second World War compared to the local environment they currently lived in that they felt was less neighbourly due to increased materialism and competitiveness. However Cornwell (1984)

points out that participants' 'private accounts' indicated a darker side to community life in the past, such as 'turning a blind eye' to domestic violence and frequent physical fights between children.

Despite the fact that the current study takes place thirty years after Cornwell's (1984), the findings indicate that participants also portrayed similar romanticised notions of the past, indicating the continuing relevance of her study. However, since Cornwall was writing, other social changes have taken place that have had an effect on the social and community life of participants. One main change emerging from the narratives is that of the 'Right to Buy' scheme introduced by the Conservative government in the 1980s, allowing council tenants to buy their homes. It has been estimated that by 2003 over 1.5 million council houses had been sold to their tenants (BBC 2004) and a third of ex-council homes sold under the scheme are now owned by private landlords (Sommerlad 2013). For two participants in particular buying their council properties under the 'Right to Buy' scheme had led to severe financial difficulties but it has also meant that many of the properties in participants' local community are now owned by private landlords. This group of participants describe a far more transient local population, perhaps partly due to the short-term lettings of privately owned ex-council properties. They described no longer knowing their neighbours in the way that they had done in the past, perhaps because they often belonged to a very different social group than the participants. For example participants described neighbours who were university students or immigrants who spoke limited English, a stark contrast to the neighbours they had developed good relationships with when they first moved into the flats when they were 'all in the same boat', raising their families together.

These findings accord with those from a recently published interview study with 46 local residents from a range of ages and ethnic backgrounds living on council housing estates in Bermondsey and Camberwell in Southwark where many of the participants from the current study also lived (Jensen and Gidley 2016). Over time the Right to Buy scheme has led to an increase in private renting, with many flats being let as rooms, which has typically led to a high level of turnover which was found to lead to feelings of alienation among residents (Jensen and Gidley 2016). Older white participants compared positive memories of the sense of community on estates based on kinship, trust and reciprocity with present feelings of an erosion of local community and an increase in individualism in their local areas that are now run-down, very similar to the findings of the present study. As well as the increase in tenant turnover in rented properties owned by private landlords bought under the Right to Buy scheme the study found a number of other reasons explaining these views of older residents. Older residents reported that council housing policy changes meant their children were no longer given priority for council housing and so had moved out to other areas where housing was more affordable (typically Kent) as had many of the children of participants in the current study. Older residents also reported that the increase in immigration that they had witnessed over their lifetime had led to some racial tension, particularly with some older White British residents feeling the black population (with Black Caribbean being the largest minority ethnic group in Southwark, as well as Lambeth) had been given priority in the allocation of council housing over their own children. However the residents were found to have experienced a more significant social divide due to the 'gentrification' of the area, referring to expensive private housing developments in the former docklands, increasing the socio-economic divide between the affluent professionals living there and the local residents of

council estates. Although in the current study participants were not specifically asked about their views on housing and community, many white British participants touched on similar views concerning the changes they had witnessed in their local neighbourhoods over their lifetimes and the erosion of a sense of community and kinship, indicating the importance of housing and community in their self-presentation.

As with participants in the current study, Hillcoat-Nalletamby and Ogg (2014) found that with increasing age people are more likely to report dislikes of their neighbourhood due to a lack of sense of community belonging and inclusion (based on data from the 2004 Living in Wales Survey of over 4000 people aged 50 and over). The authors found that for respondents who reported at least one dislike about their neighbourhood this was most likely due to young people 'hanging around', (12.3%), poorly maintained environment (9.9%), dislike of neighbours in general (8.1%) and noisy environment (8%). These were all dominant topics in the self-presentation of Ted and Rita, Richard and Judy and Ethel. However, as discussed, most participants expressed a desire to stay living in their current home with many feeling that they were 'too old' to move from an area where they had lived for the majority of their lives. Findings from the 2004 Living in Wales Survey suggest that the likelihood of wanting to move decreases with age but those with a long term illness or disability (just over a third of the total sample) were more likely to contemplate moving, particularly if they felt this had an impact on their ability to remain mobile and autonomous at home (Hillcoat-Nalletamby and Ogg 2014). This relates to the experience of Richard and Judy who were the only couple who expressed a strong desire to move, due to Richard's poor health and disability and the unsuitability of their current home in a high rise tower block.

Participants' descriptions of the changes in their local neighbourhoods and perceived lack of community provides support to the notion of low social capital. Social capital 'refers to connections among individuals - social networks and the norms of reciprocity and trustworthiness that arise from them' (Putnam 2000:19). Based on research mainly in the US, social capital is argued to be a key mechanism in the relationship between poverty and ill health (Putnam 2000). Measures have been proposed to strengthen social capital (for example by promoting local social organisations and networks in economically deprived areas where social capital was low) in order to improve health outcomes as well as other outcomes such as increased educational achievement and reduced crime. In the UK, findings from case studies based on in-depth interviews with residents of various ages from two deprived areas in East London found that neighbourhood characteristics, such as housing, services and facilities, as well as individual's experiences, such as unemployment and ill health, had an impact on social exclusion, including a reduced capacity to access social capital, and poorer health chances (Cattell 2001). In one of the areas of East London alienating housing design, anti-social behaviour, and high population turnover in particular were identified as barriers to developing and sustaining local social networks, and undermining any sense of community. The current study indicates that these findings also have relevance to people of advanced older age living in deprived areas of South London. The group of seven participants who presented housing as a dominate narrative theme identified anti-social behaviour and high population turnover as issues that made it difficult for them to develop social relations with neighbours, undermining the previous sense of community that participants described when they had first moved into their homes during the 1960s and 1970s.

Self-presentation: summary

There was no single dominant theme in the self-presentation of four stroke survivors and three spouses, with their narratives spanning across the different themes. Ted (and his wife Rita) and Patrick (and his wife Betty) focused equally on stroke and other ill health, work and retirement and housing and community. Sarah (and her husband Nelson) focused on the stroke but also talked about their previous working lives. Sheila focused little on the stroke but discussed much of her past identity in terms of work, during the Second World War, while living in Australia when she was younger and in the UK, particularly her work as a local councillor, and also bereavement in relation to the death of her husband.

In summary, the first dominant theme of self-presentation of 15 stroke survivors (and 11 spouses) was the stroke. Five of these stroke survivors' narratives focused on their poor health and hardships of their daily lives indicating a poorer quality of life, whereas the other ten gave a more positive, stoical self-presentation, discussing the aspects of their life they felt grateful for, often their family members, with some drawing on downward social comparisons of others who were worse off and discussing their lower health expectations in old age.

Work and retirement were the second dominant narrative theme for eight stroke survivors (and three spouses). For these participants from working class backgrounds, past experiences of work were important to present themselves as hardworking and useful, establishing their moral worth, distancing themselves from the negative connotations of stroke and other ill

health and old age. Importantly it was not the nature or status of the work that appeared to be of significance in self-presentation but it was the presentation as hardworking, honest and financially self-sufficient.

The third dominant theme of self-presentation for a group of six stroke survivors was their experience of loneliness and for five of them this was linked to bereavement due to the death of a spouse or child. Importantly, findings highlighted that for these participants the experience of bereavement had been a biographical disruption rather than the stroke. The impact that the loss had had on their life was more significant rather than the length of time since bereavement as for most this has occurred a number of years ago.

Finally the narrative theme of housing and community dominated the narratives of four stroke survivors (and three spouses). The narratives of two stroke survivors focused on the financial problems they were experiencing due to housing issues and another stroke survivor and his wife were living in housing that did not meet their needs due to limited mobility as a result of the stroke and other health conditions. For two stroke survivors (and one spouse) their narratives discussed experiences of crime and anti-social behaviour in their local neighbourhoods, illustrating a general wider theme about the changes in the nature of the local community over their lifetime. All participants had sought help from different authorities about the housing issues and anti-social behaviour they had experienced, however all felt they had not received the support they needed.

I now turn to a discussion of participants' narratives within the context of biographical disruption.

Stroke as biographical disruption

Bury (1982) conceptualised chronic illness as biographical disruption based on Gidden's (1979) notion of a 'critical situation' that can be drastically disruptive to the structures of everyday life, leading to overwhelming and dominating uncertainties. Building on Bury's (1982) work Williams (1984) put forward the concept of 'narrative reconstruction' to describe the process of how people manage biographical disruption and attempt to make sense of this change to reconstruct a sense of order and purpose. It was clear that some participants, despite the physical, emotional, psychological and social impact of the stroke, drew on different resources to attempt to reconstruct their biographies, which I now discuss.

This section examines stroke in the context of biographical disruption and discusses seven participants (Bob, Mary, Tim, Martha, Delia, Eric and Irene) whose narratives' clearly indicated that stroke had been experienced as a biographical disruption, with each discussing the ways in which the stroke had impacted on their life and how they felt about this. While some moved on to talk about life after the stroke, attempting to make sense of the stroke through their narrative, others did not. I now discuss biographical disruption following stroke, within the context of work.

Stroke, work and biographical disruption

Three participants had been working at the time of their stroke (Bob, Mary and Eric) and had experienced the stroke as a disruption because they could no longer work, which had been essential to their identity and to their financial independence. They had all worked in routine occupations; work had been

a significant part of their identity and they had presented themselves as having a strong work ethic, as did the other eight stroke survivors and four spouses who talked about work in their self-presentations discussed earlier. Not being able to work had also had a significant financial impact for the participants, particularly for Eric and his wife Irene.

Bob (aged 87) was a widower who lived alone in a flat he rented from a housing association. He had had his stroke six months ago while on his way home from work. He was getting off a bus intending to stop in at a local supermarket and described 'not feeling well at all' so he asked a man to call an ambulance which took him to hospital. When he did not arrive at work the next day a colleague called his home and then the local hospitals when he did not answer. When she found out he was in hospital she informed his only son who lived a couple of hours drive away. He was in hospital for three months after this.

Bob talked about how he felt forced to retire initially at age 65 by the large company he worked for and had described this in terms of a biographical disruption. Therefore he had chosen to take on part time paid employment in a concierge-type role in an office building.

My wife didn't want me to get a job (after I retired) but I said yes I will. I phoned the office, I started there because I was bored and short of money, it's as simple as that and of course I was living nicely then when I was getting a wage coming in from there for five hours (a day) and my pension and my wife's pension.

(Bob, widowed, aged 87)

Having a stroke led to an enforced, abrupt (second) retirement and Bob experienced stroke as a biographical disruption because it meant he had to give up work which had been such a significant part of his identity. He talked about how much he valued the social aspect of meeting people at work, the structure it provided to his day and the financial independence it gave him. He presented himself as having a strong work ethic and talked about how much he now missed working.

It was a good firm while it lasted, well I was there 22 years... they kept me on, let me stay there as I was 87 before I had the stroke. Well it wasn't practical for me to stay there after I'd had a stroke. Not from their point of view certainly and nor mine... But I do miss that because it made a break by meeting people first thing in the morning you see. Something to do and something to say because I didn't do a lot sitting on the desk... everything was going all right you know. I thought it was going on forever to tell you the truth and suddenly it hits you.

(Bob, widowed, aged 87)

Here Bob says that prior to the stroke he felt that he would continue to work 'forever', implying that the stroke was experienced as a major disruption to work that was a 'taken-for-granted assumption and behaviour' (Bury, 1982) that played such an important role in his life.

Bob was the participant who had experienced a stroke most recently (six months prior to his interview). He did not seem to have adjusted to the change in his life and therefore did not engage in narrative reconstruction at all. Despite not having left his flat alone since his stroke and having to use walking sticks to get around his flat, he spoke about wanting to try to go out

for a walk down the road alone and possibly get on a bus but said his son had told him not to try to do this as he would risk an accident. Bob thought that his son was being overprotective and that he was capable of being able to walk outside alone. He appeared to be struggling to accept his limited mobility and the effect this had on his life due to the relative recency of the stroke. Had he been interviewed at a later date his narrative and self-presentation may therefore have been very different. This indicates that a certain period of time is necessary for the process of socially and psychologically adjusting to changed circumstances after stroke, before narrative reconstruction is a possibility.

Mary (aged 75) was a widow who lived alone in a council flat. She was at home when she had the stroke seven years ago and her teenage granddaughter was staying with her at the time. She described feeling 'disorientated' and 'all twisted' on the sofa and making her way to the kitchen to bang on the wall so that her granddaughter would come from the bedroom, but she could not hear at first as she was listening to music using headphones. Her granddaughter called an ambulance and Mary described being delirious when she first arrived at the hospital, where she stayed for two weeks.

After her stroke Mary had also had to stop working as her eyesight had been badly affected. Like Bob, she talked about feeling forced to retire initially at age 60 by the large company she worked for and had described this in terms of a biographical disruption, saying that retirement had been a 'shock' and that left her feeling 'completely shattered'. She had then taken on regular cleaning and babysitting jobs for families and had really enjoyed this work

and had developed good relationships with the families and talked about a well-known TV personality she had worked for.

I retired when I was 60, which took me two years to get over the shock. I'd made up my mind I was staying in work till I was 65 but I worked for (a large telecommunications company) and they were quite adamant that you went at 60. I was on a computerised help desk. Took me nearly two years to get over the shock of retirement... I was completely shattered (when I had to retire at 60). I mean I'm what 75 now but inwardly I'm 27.

(Mary, widowed, aged 75)

Like Bob, Mary had also experienced the stroke as a biographical disruption as it led to an enforced, abrupt (second) retirement from a job that had been such a significant part of her identity. She talked about how she had always worked since she was a teenager, not even stopping work for long after she had given birth to her daughter. She took pride in her work and valued its social aspect and the financial independence it gave her.

I do miss (work)... If I hadn't had my stroke I'd still be doing my (paid) housework probably. It was every day. Sometimes on a Sunday as well. I used to baby-sit for them as well, about five or six families. I started off with one but by word of mouth it goes all round... They were lovely people to work for. It was lovely because I get on with everybody. When I used to clean their homes, it wasn't their home I was looking after, it was mine. I never nosed in any cupboards.

(Mary, widowed, aged 75)

However, unlike Bob, Mary engaged in narrative reconstruction to make sense of why the stroke happened and to present herself as a positive person determined to make the best of life. It had been seven years since Mary's stroke, and it appeared she had adjusted to life in comparison to Bob who had had the stroke only six months ago. Mary spoke about how her sister had had a heart attack and was in hospital after heart surgery and she had been travelling there and back to her sister's house to help out her brother-in-law with housework. She believes it was the stress of this that led to her stroke. She engaged in a very positive self-presentation, presenting herself as an independent, stoical woman. Mary had been a widow for 20 years. However unlike Joan, Derek, Alfred and Sheila who were lonely and talked about how they missed their spouses, she talked about how much she enjoyed living on her own and having the freedom to do what she liked.

I've been on my own 20 years, I love being on my own, I love my own company. I like my telly, I read a book. If I want to indulge in a bottle of wine, or something I'm free to do what I like when I like. I mean for years and years and years I never bought bacon because my husband didn't like bacon, so he didn't like bacon, so I didn't buy it. But now I, I just, I eat what I like. If I want to indulge myself in something a bit special food wise I can buy it.

(Mary, widow, aged 79)

She went out by herself every day and despite having limited eyesight she preferred to go out alone rather than depending on anybody and would ask strangers to help her cross the road.

It seems to me that it's when I've got somebody with me (when I go out), I seem to not be able to, I think I must rely on them and it makes me feel, what

shall I say, not as independent as I am when, knowing when I've got to go out on my own, if that makes sense. Um but um, I mean I'm not adverse sometimes, If I go out to the bus stop and I want to go, and I have to cross the road I will stand there and I will ask somebody be it male, female, black, white, I don't care. I will ask somebody, will you be so kind as to take me across the road, I've got bad eyesight. One person did turn round and say why haven't you got a white stick then and I thought oh well never mind... my grandchildren are very good. They come and they sort of take me out and what have you, they're very good but as I say when they're with me, apart from them saying Nanny, Nana are you all right and then I say yes and then I get a bit wobbly and what have you um but all in all I'm better on my own. Do you know what I mean, I've got to go and do these things.

(Mary, widow, aged 79)

Mary had a daughter and grandchildren whom she saw regularly. Her daughter had recently been diagnosed with cancer and was currently undergoing radiotherapy which Mary described as 'a bit traumatic'; she went to see her daughter as often as she could to help with the washing and ironing. So despite being partially sighted since the stroke she was engaging in a caring role for her daughter. Therefore although she initially experienced the stroke as a biographical disruption, particularly as she had to give up work which had been very important to her identity, she engaged in a narrative reconstruction to make sense of the cause of her stroke and presented herself as a positive person who was living as independently as possible, and emphasised her maternal role in caring for her daughter and grandchildren.

Eric (aged 79) and his wife Irene (aged 77) were Irish and lived in a rented council house. Eric was working as a builder at the time of his stroke fifteen

years ago. One evening after he had come home from work he was in the bathroom and had turned the bath taps on but was then unable to turn them off. He shouted for help and his son, who had just come home, put him in the recovery position and called an ambulance. His wife Irene had to stay at home to look after their granddaughter. Eric was in hospital for 13 days and was partially paralysed on one side and had slurred speech. When he came home he could not walk well and had physiotherapy. Gradually his mobility improved and he was now able to walk down to the local shop for a newspaper. A year after this he was diagnosed with diabetes and a year prior to the interview he was fitted with a pacemaker and had also been diagnosed with asbestos poisoning as he had worked in the building trade all his life. Eric and Irene had experienced the stroke as a major biographical disruption, particularly because Eric was no longer able to work and this had affected them financially. Irene spoke about feeling 'degraded' and 'humiliated' when she had to go to the local 'DHS' to claim benefits after Eric was unable to work after the stroke. They presented themselves as hard working people, proud that they had always worked since they had moved to London when they were young and had always 'paid their way' and so had found it particularly difficult having no alternative but to rely on benefits. Irene said this experience had made her feel more understanding towards others who had experienced ill health and had suffered financially as a result.

He was so long out of work (after the stroke)... (Claiming benefits) was very degrading. And then you've got to come back to a man who's not very well and try and get on with your life it's very hard... When you work all your life and pay your way and as soon as your health takes a belt you realise how cruel people really are but I got over it and I'm still here... It hit him hard because he's always been a worker.

(Irene, wife of stroke survivor, aged 77)

However they had also experienced other hardship in their life; the poor health and disability of their daughter Claire also emerged in their narrative. Until recently Irene had been caring for both her husband and Claire who had also had a stroke a few years ago and was partially paralysed. Their daughter, aged 44, was born with dwarfism and also had numerous health problems as she was a diabetic dependent on insulin, was epileptic and had another hereditary condition that mean she was iron deficient. She had been living away from home with a boyfriend who had been physically abusive towards her and she had once been in hospital for five weeks after he had abused her. A few years ago she had left her boyfriend and moved back in with her parents. Irene talked about Claire's complex needs, both physical and emotional, and described her as having a split personality, being 'beautiful' and 'cheerful' one minute and very difficult, demanding and self-absorbed the next. Claire had suffered from epileptic fits and after one particularly severe fit nine months prior to the interview, with Irene describing her behaviour as a 'devil possessed', Irene told social services she could no longer cope so Claire was now in respite care.

I: (My daughter) Claire is also a stroke victim... she's insulin dependent and I was looking after her until it was affecting my health, she's in respite care now unfortunately, yeah, very stressful... there's a lot of self-righteous people out there who would say I wouldn't leave her in there, she's a wonderful person, beautiful personality...she was also epileptic...she's taken every bit of last strength out of my body... so they've put her in respite.... I'm 73 years old, I can't, I'm not ashamed to say it, I can't cope anymore but I see to it that she's got everything she needs...

E: Every week she's goes down there (to the respite care home), don't you.

I: You can't hate her but I can't live with her either, you know. It's another tragedy with Eric's illness.

(Eric, aged 79, stroke survivor, Irene, aged 77)

Eric and Irene seemed to feel a certain amount of guilt for Claire having to move out of the family home to live in respite care. During the narrative Irene talked about feeling judged by others who did not understand her circumstances. She spoke in detail about how hard it had been to care for her daughter, providing an explanation and justification for her decision to tell social services she could no longer cope with her at home.

Although Eric's stroke had been experienced as a disruption at the time, particularly because it meant he could no longer work and they had suffered financially, they were also used to experiencing hardships which contributed to their stoical self-presentation. Irene and Eric felt that their religious faith had helped them cope with the hardships they had experienced and Irene said she had a lot to be grateful for as she had three other children and grandchildren and they had been married for 50 years. Eric's stroke had occurred 15 years ago so they had had many years to adjust to the disruption. For Irene and Eric, the more recent experience of their disabled daughter moving back in with them after many years of living away from home and Irene taking on the role as her full time carer, as well as Eric's, and then subsequently no longer being able to cope and her moving to respite care, had been experienced as a more recent biographical disruption. Therefore this experience had also been an important theme in their narrative as well as Eric's stroke.

This section has discussed the ways in which some participants had experienced the stroke as a biographical disruption particularly in relation to work. The next section discusses biographical disruption and narrative reconstruction as a response to this.

Stroke, biographical disruption and narrative reconstruction

First this section discusses the narrative of a participant who engaged in the process of narrative reconstruction after initially experiencing stroke as a biographical disruption. Second, the narrative of a participant who experienced the stroke as a biographical disruption but did not demonstrate narrative reconstruction is discussed and the possible reasons for this. Third, the narrative of a participant who engaged in a process demonstrating biographical reinforcement, rather than biographical disruption, is presented. Martha (aged 79) was originally from the Czech Republic. She lived alone in a flat that she owned and had previously worked as an editor and manager in education and publishing before retiring. She had originally had a stroke 20 years ago after dental surgery and although this was not diagnosed at the time she feels very strongly that in the light of two transient ischemic attacks and another stroke over the previous two and half years, it was a stroke. She was in hospital for two nights after the most recent stroke. She experienced some difficulty moving around but was able to walk unaided. She had aphasia which meant she sometimes got words mixed up and spoke in quite a slow stilted manner, appearing to think about many of her words before she spoke them. She had a daughter and two teenage grandsons who she saw quite regularly.

Her most recent stroke had been experienced as a biographical disruption, particularly as it had affected not only her mobility but also her speech. She said she felt very conscious of her aphasia and said she tried to think carefully about the words before she said them. However her narrative indicated that she was engaging in reconstruction to make sense of the stroke and to create a new sense of order in her life. She strongly believed it is an individuals' moral responsibility to look after themselves and manage their own health, particularly after a stroke to ensure they are not a burden to their family or anyone else. She engaged in what she called 'self-help' by 'retraining' herself with exercises to improve her 'brain' and speech, performing physical exercises and participating in a local over 65s group and local exercise groups and creative writing groups. She was very active in the local community and was an active member of a stroke research service user group. Martha presented herself as someone who is independent and an 'active patient' engaged in 'retraining' to improve herself mentally and physically after the stroke but also to prevent another stroke. In this way she is presenting these actions as something that she has a moral responsibility to do in order to prevent herself from being a 'burden' to her daughter, the health service and society in general. She also talked about wearing a 'do not resuscitate' pendant to ensure she does not have to be dependent on anyone or become a 'burden' to her daughter. In these ways she is reconstructing her biographical narrative as someone taking moral responsibility for her own health, doing all that she can to prevent herself being a burden on her family or society. Martha was attempting to create a sense of order and purpose, rather than letting the stroke dominate her life. This links with other research findings from older people with arthritis who were keen to present themselves as independent and not as a burden to society or their families (Sanders et al., 2002). 'Becoming a burden' to family

and friends has been identified as one of the four sources of loss of self by people who are chronically ill (Charmaz, 1983) and Martha was attempting to avoid this at all costs.

I think self help should be another rule to apply. And get the advice and then help yourself if you can... (When I came home from hospital) my daughter has, is very busy and has these two boys and rebuilding the house and all that. So it's a normal story of modern times that the younger generation is in a different position and so is the older one. So I couldn't rely on that, and I wouldn't like to because it would bring a horrible extra burden for her, and who would, you know, I know what it means to take care of these two boys. So I wouldn't – it is a horrible idea that she would have to take care of myself as well. So that's why I keep trying to keep myself healthy as I can. It's very important. On the other hand, I have this, 'Don't resuscitate' instruction, with me all the time. I have a note which I left with the GP, and I feel it's now the time when these problems are reassessed, I mean nationally, and it would be probably a great relief for many older people to have a more reliable idea of what happens if they don't want to be treated over a certain level. And how it could be arranged.... I think it's almost imperative (to do as much as you can to prevent another stroke) because you couldn't live with yourself not doing it, because if it happens, you think, 'Gosh it's God's will or somebody's will, but I didn't contribute too much to it.' But to live with the feeling that you've sort of inflicted it on yourself through folly or excess, I wouldn't like to live with it and then be somebody's burden is a horrible thing, which is true about the whole life if one is reckless, but with health it's not the best idea. But after stroke, it's, one shouldn't get drunk or smoke, I don't have cigarettes and do the other things like that.

(Martha, aged 79)

Delia (aged 75) and lived alone in a house that she owned and had been divorced twice. Eighteen months ago she had had major dental surgery to have tooth implants and the surgeon had found that she had a 'nasty abscess' and she described a lot of bleeding but said she felt no pain as the 'nerve of the tooth had been killed'. A week after the surgery she had to have the stitches out and it was then that the stroke began with what Delia describes as feeling very tired with a 'massive headache'. She said she thought she was going to die. After she had managed to get home on the train she called one of her daughters and ex-husband who was a friend, and they called a GP who visited her at home. She told him what was wrong and he examined her and said he was 'puzzled' and 'walked away'. She called her dentist who 'said it's not his fault'. Two days later they called another GP who recognised that she had had a stroke and told her to go to hospital immediately. Delia was very upset and angry about the first GP not recognising that she was having a stroke as this prevented her from getting to hospital for treatment right away. She felt he should be 'stuck off' and wrote a letter of complaint to the practice about the GP.

Delia had experienced her stroke 18 months ago as a major biographical disruption but unlike Mary, Tim and Martha, she did not engage in narrative reconstruction. She was now able to walk but not long distances and had problems with balance and fatigue, and her vocal cords had been affected by the stroke. Like Bob, her narrative indicted that she was struggling to accept the impact the stroke had had on her life which could also have been due to the relative recency of the stroke compared to other participants, therefore she did not engage in a process of narrative reconstruction. She felt that the impact of the stroke on her life was worse because she did not have a partner

'who'll help me and who I can help', indicating the importance of the reciprocal relationship between a couple. In a similar way to the five bereaved participants who talked about feeling very lonely, she also appeared to be lonely, describing herself as feeling 'miserable' and 'vulnerable'. She felt unsupported after the stroke both by health and social services and by her family. She had three daughters but felt they did not understand what she was going through after her stroke.

I didn't realise that when something awful happens to you that physically affects you, you're virtually pushed out into the world like a little bird from a nest and you've got to cope with it yourself. I have to manage my treatment.... Normally my life is full of doing sort of cultural things which I almost can't do anymore. Well with a big effort I can or with someone's help... Recently I've started to feel a bit more miserable about, you know, the outcome of having had a stroke... You have to keep coming to terms with the fact that you can't do what you used to do....I suppose I am sort of suffering from the fact that I don't have a partner who'll help me look after myself and who I can help. You know so that's the tough bit really. If you're well, it doesn't matter how old you are or anything, what matters is that you can get up and walk out and do things and everything but when you can't um when you can't easily you're much more vulnerable.

(Delia, divorced, aged 75)

Although Delia does not discuss the experience of losing a loved one her experience of loneliness was very similar to the group who discussed their experience of bereavement. The major difference was that Delia felt her loneliness was due to the stroke because she could no longer do the things she enjoyed doing (relating to the concept of 'social loneliness') and having

a stroke highlighted to her that she was without a partner to rely on for physical and emotional support (relating to the concept of 'emotional loneliness' (Weiss, 1973)). Therefore Delia experienced the stroke as a biographical disruption. However she did not engage in a process of narrative reconstruction, likely to be partly due to the high level of disruption on her life and the relative recency of her stroke.

I also argue that the group of participants who discussed bereavement experienced this as a biographical disruption rather than the stroke. Although biographical disruption is a term usually applied to the experience of illness and disability, the way in which these participants presented their experience of bereavement and subsequent loneliness indicated that this was experienced as biographical disruption or a 'critical situation' drastically disruptive to the structures of everyday life, leading to overwhelming and dominating uncertainties' (Giddens, 1979). Related to this, Williams (2000) discusses the notion that biographical disruption can also be a cause of chronic illness when he 'revisited' Bury's (1982) theory of biographical disruption. As discussed above in the section on loneliness and bereavement, Rose's experience supports this argument as her daughter's unexpected death appears to have been experienced as a huge biographical disruption that she believed caused her stroke only one week later. The experience of the death of a loved one and the subsequent loneliness was presented as such a major biographical disruption in the lives of this group that engaging in a process of narrative reconstruction to give a new sense of order and purpose in life was not a possibility for them.

Delia's narrative of life after her stroke suggests that some without a partner or spouse to help support them physically and emotionally after a stroke, may

experience the stroke as more of a disruption than those who have a partner. Stroke survivors who receive help and support from a partner may find it easier to continue with some aspects of their life and therefore find it easier to reconstruct disrupted narratives, which is an under researched area. I examine co-constructed narratives of stroke survivors and their spouses in Chapter Five.

One participant in particular presented a narrative that demonstrated the way in which his stroke reinforced a continuation of his working life and his biography as an activist in local politics and trade unions. Tim (aged 75,) lived with his wife in a house that they owned. Two years ago he was getting ready to go to his regular cycling session at a local velodrome when he ‘suddenly felt something was happening in my, around my eyes’ and he realised he was having a stroke. He called his wife and she called an ambulance. He was taken to hospital where he received thrombolysis treatment (clot busting drugs). Although Tim had initially experienced the stroke as a disruption as he said he had not suffered from illness since he was a child and found he had to adjust to no longer being able to do many things that he used to enjoy such as cycling and DIY. However he felt he had made a good recovery and joined the ‘Stroke Governor’s Board’ of the hospital as he felt it was important that he was speaking from experience and representing other stroke patients. He spoke about how he had been invited to join this board by hospital staff and had then been invited to meet the Health Secretary, Alan Johnson. He told the minister about how lucky he felt to be alive as he had made a good recovery from the stroke as a result of thrombolysis, and that if he had gone to the other local hospital he would not have been able to receive this treatment as it was at a weekend. This narrative supports Carricaburu and Pierret’s (1995) notion of biographical reinforcement based on their findings

that being HIV positive reinforced the identities of haemophilic men and homosexual men. Tim's narrative of stroke reinforces his identity as a local political activist and a trade unionist who seeks to represent what he refers to as the 'underdog'.

Tim talked about his work for a trade union and his role in local politics, some of which he had had to give up since the stroke. However he still felt he was active in terms of participating in the 'Stroke Governor's Board' and talked about possibly visiting and supporting stroke patients in the future. He presented himself as a campaigner for social justice and felt it was important that he does something useful as he doesn't want to be seen as a 'vegetable' after the stroke. So although the stroke had left him with limited mobility (he had problems walking long distances and was unable to carry on his hobby of cycling etc), his narrative of his stroke was a continuation of his biography as a trade unionist and a campaigner in local politics.

On the day, I think I was discharged, (the nurse) said, 'I'd like you to become a member of the Stroke Governors Unit as a patient representative.' She said, 'I know you can use a computer, you appear to be fairly literate, and you're not frightened to stick up for yourself and other people, and I really would welcome that.' So I did.....I was invited to go back... (to speak to) the Health Minister, and that was great to sit and have a one to one with him...I was able to tell him what had happened to me...when he left he thanked me and asked me how I'd got involved with this. And I said, 'Well old trade union habits die hard, you know, Alan.' And I knew he was one time leader of the Post Office Workers Union. And he said, sort of blushing, you know, 'Hmm, which union were you in then?' And I said, UNISON, but prior to that, a long, long time ago, the ETU.' And, 'Oh yes,' he said, 'There was,' because it had

a reputation for being communist... I think in some industries electricians were, probably got a better education, they were more literate. And so, of course, they fought the corner better. But it was great to, erm, it was great to talk to him. And so that was another spin off from being on the Stroke Governors Unit.

(Tim, married, aged 75)

Tim's narrative corresponds to a 'quest manifesto' illness narrative, characterised by demands for social action and special insights gained from illness experience that the narrator wants to use to improve others' lives (Frank 1995). In their application of Frank's (1995) narrative typologies to stroke survivors' narratives, France et al (2013) did not identify any narratives that were in line with the 'quest manifesto' type, perhaps indicating it is not a common narrative type presented by stroke survivors. They found that most participants presented a narrative in line with a 'quest memoir' type where the illness is incorporated into life, and trials are told stoically, corresponding to the group of ten stroke survivors in the present study who engaged in positive self-presentations, discussed earlier (see page 97).

In summary, the narratives of these six stroke survivors and one spouse indicate that they had all experienced stroke as a disruption to their biography mainly due to not being able to continue work or because of the recency of the stroke. Martha, Tim, Mary, Eric and Irene all engaged in a process of narrative reconstruction as a way to make sense of the stroke. However Bob's and Delia's narratives did not indicate a process of narrative reconstruction. It is likely that, partly due to the relative recency of the stroke, they were struggling to come to terms with the impact of the stroke on their lives and both were more socially isolated since the stroke and were quite

lonely. It was perhaps too early for them to construct a narrative that attempted to incorporate the stroke in their biography. Other participants who had all had their stroke over two years ago, had had more time to adapt and to incorporate the stroke into their biographies.

Discussion

This chapter has examined the self-presentation of stroke survivors aged 75 and over to address the research questions ‘how do older people talk about themselves following a stroke?’ and ‘to what extent is stroke experienced and interpreted as a biographical disruption by people of advanced older age?’. The findings have drawn on Goffman’s (1959) notion that identity is constructed during social interactions in everyday life through the presentation of self and Giddens’ (1991) concept of the self as a set of reflexive biographical narratives that continually integrate life events in the external world.

In answer to the research question ‘how do older people talk about themselves following a stroke’, one group of participants’ focused on their poor health and hardships of their daily lives in their accounts of stroke. This was in line with notions of the ‘fourth age’, a period of old age characterised by serious illness, functional decline, frailty and physical dependence (Laslett, 1989). However others gave a more stoical account, drawing on downward social comparisons of others who were worse off and discussing their lower health expectations in old age. They presented themselves as generally positive, trying their best to live as independently as possible, supported by previous findings showing the importance of maintaining a positive sense of

self and remaining as independent as possible for older people's identity (Tanner 2001). These participants appeared to be distancing themselves from the negative stereotypes of old age and ill health. The current findings are also supported by previous findings that older people tended to minimise the impact of stroke, viewing it as a natural part of the ageing process (Pound et al., 1998; Faircloth et al., 2004) and were keen to present themselves as independent and not as a burden to society or their families (Sanders et al., 2002).

The current findings extend previous findings demonstrating that stroke was experienced as a 'normal crisis' for working class stroke survivors living in the East End (aged 40-87) due to previous experiences of crisis and hardship and familiarity with the worlds of pain, suffering and death (Pound et al. 1998). In the current study life experiences relating to work and retirement, housing and community, and bereavement and loneliness meant that for some the stroke was experienced as another hardship in life rather than as a biographical disruption.

Participants from working class backgrounds who talked about themselves in relation to work and retirement drew on past identities and roles to emphasise how hard-working, honest and self-sufficient they were, disassociating themselves from dependence on state welfare and resisting the stigma of old age. It was not the nature or the status of the work that was of particular importance in self-presentation, but the self-presentation as hardworking, honest and financially self-sufficient people. These were examples of 'moral narratives' providing accounts of changes between the person, the illness and social identity, and which help to (re) establish the moral status of the individual or help maintain social distance (Bury, 2001). In her study of

attitudes towards health and illness held by people living in a deprived part of East London, Cornwell (1984) also identified a structure of moral belief related to the 'capitalist work ethic' that underpinned attitudes towards work, health and illness. She found that even when a person was ill or retired it was important for them and others to 'establish their credentials as (previously) good workers and as people who have never not been willing to work' (1984: 71). The current findings are important as they indicate that this continues well past retirement, into old age, possibly becoming even more salient in old age when older people may be more likely to experience insecurity and uncertainty about their role in a capitalist society where identities are strongly linked to the roles of producer and consumer (Phillipson, 1998). This is perhaps even more important for those who had previously worked in lower paid jobs who are more likely to experience a lack of financial security in old age compared to those who had been employed in higher paid jobs.

For another group their talk about themselves following stroke centred on loneliness and bereavement and it was the impact of the loss on their life that was significant rather than the length of time since the bereavement. Importantly the findings show that the experience of the death of a loved one and the subsequent loneliness were presented as a major biographical disruption in their lives, rather than the stroke, and engaging in a process of narrative reconstruction to give a new sense of order and purpose in life was not a possibility for them. The death of a spouse can result in the highest level of life change (Elder and Rockwell, 1979) and for those participants whose daily routines are more fixed around their spouses the structure of their life can be more substantially altered after the death of a spouse (Hildon et al., 2008). This implies that for the four participants in this group who had

been widowed, their daily routines had been more structured around their spouses and therefore they experienced the bereavement as more of a disruption than other participants may have. It is important to acknowledge that this group had experienced a slightly less severe stroke in comparison to some other participants as their mobility was less affected. Therefore had any of these participants experienced a more severe stroke, this may have featured more prominently in their narrative and perhaps may have been experienced as more of a biographical disruption.

Housing and community was a theme that dominated the narratives of another group of participants who had lived on the same council housing estates for most of their lives. This provided an important context to their experience of stroke in older age, illustrating the wider social and policy issues regarding older people staying in their own homes or 'ageing in place'. In an overview of government policy since the 1940s 'ageing in place' has been a 'seamless and almost endless policy commitment' (Means, 2007: 67), but since the late 1980s there has been criticism of community care policies for their lack of focus on housing. The current findings lend support to a study on the housing issues of vulnerable older people in different areas around the UK that found participants were active agents in their own housing situation rather than passive victims (Means, 2007). Means (2007) concluded that for 'ageing in place' to maximise quality of life for vulnerable older people, mainstream housing for all older people needs improvement, especially for those on low incomes, and investment in a much wider range of specialist support and advice services is necessary. The participants in the current study who discussed housing and community would have benefitted from a wider range of support, for example Ethel, Patrick and Betty, and Richard and Judy indicated that they had all been unable to receive the specialist support

that they had sought. All of these participants would also have benefitted from an improvement to their housing or from a move to more appropriate housing to meet their needs. However five of the seven participants in this group indicated they wanted to 'stay put' and age in place supporting other research findings that the vast majority of older people value 'ageing in place' (World Health Organisation, 2007). However, drawing on data from the 2004 Living in Wales Survey and a critical review of the literature, Hillcoat-Nalletamby and Ogg (2013) argue that older people's level of satisfaction with where they live should not be viewed uncritically as a premise for policy makers to promote ageing in place. Despite the majority expressing a desire not to move, many participants in the present study expressed dislikes with their neighbourhood, mainly due to a lack of sense of community, antisocial behaviour and a poorly maintained local environment. Therefore as well as the suitability of older people's housing, this points to important issues with older people's local environment that need to be addressed within the context of ageing in place, particularly in relation to older people from low-socio-economic and vulnerable groups, including stroke survivors, living in social housing.

Unlike Bury (1982) who focused on participants who were newly diagnosed with rheumatoid arthritis, Pound et al (1998) who interviewed participants 10 months post stroke and Faircloth (2004) who interviewed stroke survivors at five intervals from one month to 24 months, the present study makes an important contribution in terms of its focus on a longer period post stroke. Participants had a stroke six months to 15 years prior to their interview, with the majority having had the stroke within the last three years. Some participants may have initially experienced the stroke as a disruption to biography but had time to adjust to their changed circumstances after the

stroke and engage in a process of narrative reconstruction and move on (which was a concept developed by Williams, 1984, based on interviews with people who had had rheumatoid arthritis for at least five years). Over time stroke may have less significance for participants' biographies, partly explaining why the other themes of work, loneliness and bereavement and housing and community dominated some narratives. Therefore it is important to acknowledge that the narratives focus on one point in time and the findings indicate that these are partly influenced by the period of time after stroke which supports the argument that the concept of biographical disruption has a temporal dimension as it was developed in relation to people experiencing the onset of chronic illness (Delbene 2011).

In answer to the research question 'to what extent is stroke experienced and interpreted as a biographical disruption by people of advanced older age', stroke was clearly experienced as a biographical disruption for a group of six stroke survivors and one spouse. For three this disruption was because they were no longer able to work and this had a disruptive impact on their identity as well as their finances. This relates to studies of younger participants with chronic illness that found that work represents normality after chronic illness and returning to work was one strategy used to maintain identity (Charmaz, 1994, Hubbard et al, 2011). For the other three participants the stroke had been experienced as a disruption due to the effect on mobility (and speech) and therefore their social world had changed and they were no longer able to enjoy the things they used to. However it is important to note that whether or not people experienced stroke as a disruption was not related to severity of disability post-stroke. For two stroke survivors there was no evidence of narrative reconstruction, partly due to the relative recency of the stroke. Four stroke survivors and one spouse clearly engaged in a process of narrative

reconstruction to make sense of the stroke and incorporate it into their life story. A review of qualitative studies on adjustment post stroke identified the importance of narrative reconstruction as a resilience practice and that the interview process can be helpful in facilitating this process (Sarre et al. 2014). The current findings would indicate that those who engaged in narrative reconstruction during the interview certainly presented themselves as more stoical and resilient despite the experience of the stroke and other hardships in life, suggesting that engaging in a process of narrative reconstruction is one tool that can be used to facilitate and encourage resilience amongst older people.

The findings presented in this chapter have provided valuable insights into the how older people aged 75 and over talk about themselves following stroke, with few other qualitative studies of stroke or other chronic illness focusing on this age group exclusively. The methodological approach of using a very open biographical narrative interview method was useful in allowing participants to discuss other themes that were important to their identities, enabling a more comprehensive understanding of the context of stroke in their lives. Findings show that stroke is not always the dominant focus of older stroke survivors' narratives, illustrating the importance of other aspects of identity. Findings demonstrate the importance of past work identities in self-presentation after stroke in older age, particularly for participants from working class backgrounds. This served as a means of resisting the negative connotations associated with old age and ill health. The findings support arguments highlighting the importance of taking context into account when examining the meaning of chronic illness in older age, but in particular the experiences of bereavement and loneliness were found to be very significant for a number of participants. For some, the experience of

bereavement and subsequent loneliness were experienced as far more of a biographical disruption than the stroke. Although the experiences of bereavement and loneliness are not confined to old age, people are more likely to experience the death of a loved one, particularly a spouse, as they age. Therefore it is important to take this into account when considering the experience of chronic illness in old age, particularly in the context of providing health and social care services to an ageing population.

Findings presented in this chapter have demonstrated the significance of an individual's whole biography for the meanings they assign to chronic illness and processes of narrative reconstruction. However I argue that the meanings and disruption consequent on chronic illness need to be considered together for both the person with chronic illness and their spouse, rather than only for each party individually, which brings us to Chapter Five.

Chapter 5: Findings: Co-construction of narratives by stroke survivors and their spouses

Introduction

Support provided by social networks is identified as a contextual factor and resource that is often critical to the ways in which illness is lived and negotiated in people's lives. However the majority of studies that consider the experience of chronic illness for other members of the patients' social network have focused on the demands of providing ongoing care to a person who is chronically ill (for example. op Reimer, de Haan et al, 1998). These studies have all tended to rely on the individual interview, which as Lawton notes in the context of qualitative work, may lead to particular types of narratives that tend to give less emphasis to the 'mundane', daily aspects of 'coping with' the diseased body, despite the physical aspects of living forming the prime focus of the experience of chronic illness (2003: 35). Lawton therefore called for a shift from the dominance of the single research interview and 'opening the door to a broader range of methods and methodologies to give access to a more broad-ranging and comprehensive picture of individual illness' (2003: 35).

An important way forward is therefore to conduct joint interviews with the chronically ill person and their partner, and to focus not only on *what* is said in terms of the content of talk but also to analyse the style of the narrative, in terms of *how* people talk about and present events. A dyadic approach to the analysis of joint interview data is important for 'understanding how, and whose, stories are told about chronic illness', and for understanding the effects of the disruptions of illness on the ill person but also on their significant

other as they are central to the experience, and on the relationship between them (Polak and Green, 2015 p.4). A few studies have employed joint interviews in examining experiences and responses to chronic illness (Radley, 1989; Harden *et al.* 2006; Robinson *et al.* 2005). The largely descriptive accounts of findings have led to the suggestion that further research should focus on couples' conversational interaction to gain a better understanding of the ways in which couples engage in the construction of joint chronic illness narratives (Robinson *et al.* 2005). As discussed in Chapter Two, the small number of studies that have focused on interaction as well as content in their analysis of joint interview data have identified largely collaborative forms of interaction (Bjornholtand and Farstad 2014; Sakellariou, Boniface *et al.* 2013; Torge 2013; Morris 2001, Polak and Green, 2015). However studies have also identified some disagreements and contradictory interaction between couples (Torge 2013; Bjornholtand Farstad, 2014; Polak and Green, 2015) with some informal carers tending to take a dominant role (Manzo *et al.* 1995; Shakespeare 1993). However these studies have not employed a systematic and replicable method for analysing the interaction between couples.

As compression of morbidity has not accompanied increasing life expectancy in later life in many countries across the globe (European Health Expectancy Monitoring Unit, 2009), more older spouses will be living with long-term conditions as well as caring for a partner who also has complex morbidities (Pickard *et al.* 2012). As noted in the Chapter One, stroke is one of the leading causes of adult disability in England, with half of all stroke survivors living with a disability (Stroke Association, 2016) often having to rely on informal care from spouses or other family members. Quantitative studies have shown that spouses caring for stroke survivors experience a

considerable impact on their own health and psychological well-being (Barskova and Wilz 2007, Draper and Brocklehurst 2007). However the relationship between stroke survivors' physical disability and the level of strain and well-being in spouses has been shown to be complex because spouses well-being was not directly proportional to the extent of disability post-stroke and spouses whose partners' speech was affected by the stroke were more likely to experience strain than those without speech difficulties (Draper and Brocklehurst, 2007). Therefore qualitative research based on joint interviews is essential to provide a more in-depth understanding of the issues faced by both spousal carers stroke survivors and how the experience of stroke impacts on the relationship between the stroke survivor and spouse and their identity as a couple.

This findings chapter builds on prior studies of couples' co-construction and presentation of joint biographical narratives and aims to explore how older couples used narratives to make sense of stroke and how stroke impacted on their relationship and identities, contributing towards an understanding of how older couples assign meaning to stroke through narratives (Williams, 1984). Following on from the previous chapter which highlights the importance of social context in the experience of stroke, this chapter examines the joint interview data with 13 couples to consider the meanings and disruption of stroke for both the stroke survivor and their spouse, focusing on the way in which narratives are co-constructed by these couples. The first section examines different styles of joint narratives, referring to *how* couples co-constructed their narratives. The second section brings together the analysis of narrative style and the analysis of the narrative *content*, examining the types of co-presentation of identity that were identified.

Joint interviews began with an open question asking the couples to tell the story of their stroke, with the aim of eliciting a detailed narrative indicating how couples made sense of the stroke, what meanings they attached to it, how they presented themselves as a couple and how they attempted to locate the stroke in their overall biography. This involved a detailed reading and coding of data to identify types of co-presentation.

A further coding scheme informed by Veroff et al's (1993) scheme for the analysis of joint interviews was employed to analyse couples' co-presentation in terms of the structure of narratives and interaction. This involved coding each shift in speaker as one of six types of interaction; the first three types were categorised as collaborative styles of narratives and the last three as (explicit or implicit) conflictual styles:

1. Collaboration: *extending the idea of the spouse, questioning for information, answering questions that further the story or continuing a storyline that the spouse had previously begun.*
2. Confirmation: *a statement of agreement e.g. 'um-hmm'.*
3. Confirmation-collaboration: *an interruption that affirms the previous statement of the spouse and adds new material.*
4. Conflict: *disagreeing or interrupting the spouse with a negative response.*
5. Non-response: *explicitly avoiding responding to the spouse's previous comment.*
6. Continuation: *continuing the narrative without reflecting on the spouse's previous comment.*

Characteristics of couples

Thirteen couples participated. The couples were from predominantly working class backgrounds, with just two couples (Helen and John, Hilary and Adam) previously working in professional occupations (see table 3, page 91). None of the couples lived with other relatives, although eleven couples had adult children. Six of the stroke survivors were female, with stroke survivors aged 75-85 years and their spouses aged 59-85. Most spouses were a similar age to each other apart from two wives who were significantly younger than their husbands (Penny, aged 59, was 20 years younger than Jack; Judy, aged 68, was 15 years younger than Richard).

Stroke survivors' level of health and mobility varied but all were in poorer health in comparison to their spouses. Five of the stroke survivors were wheelchair users, three of whom rarely left their home. Three had mild aphasia; Tom and Sarah had slightly slurred speech and Tony sometimes stuttered and had difficulty finding the correct words. As with those interviewed individually, all stroke survivors had multiple chronic conditions. Although the spouses were generally in better health, with all but one able to walk unaided, eight had at least one chronic condition. Therefore spouses caring roles were often reciprocal in nature. Eleven of the couples received no help with personal care from paid carers, with many commenting that they did not want paid carers coming into their home and would rather rely on help from each other and other relatives, mainly daughters and sons. However most participants did not live very close to their children and grandchildren. Only two of the most disabled stroke survivors (Sarah and Helen) received daily assistance from paid carers.

Couples had been married for many years, with the number of years married ranging from 20-65 years, with ten couples married for 46 years or more. The marriage of the other three couples (Richard/ Judy, Jack/ Penny, Grace/ Simon) was a second marriage for both spouses and they had been married for 20-32 years. The interviews took place in the couples' homes (mainly flats on council estates) which they had shared for many years. All participants were retired and so spent much time in each other's company, sharing daily routines and rituals, for example in relation to personal care or household chores. Therefore all couples had long-standing relationships, and their shared histories and familiarity with each other came across during the interaction in the interviews. The interactional dynamics between the couples frequently shifted throughout the interview, with spouses often taking it in turns to narrate, sometimes talking between themselves while trying to negotiate their narrative, and at other times one spouse would take a more dominant role. The styles of interaction are discussed in more detail below.

Styles of narrative

Couples frequently began their narrative with a focus on the stroke event and then discussed in more detail living with stroke and other themes of self-presentation, mainly work and retirement, loneliness and bereavement, and housing and community, discussed in Chapter Four. This section focuses on the style and structure of couples' co-constructed narratives ie. in terms of *how* participants talk about and present events.

Couples' narrative styles emerged as either predominately conflictual or collaborative based on the frequency of Veroff's codes applied to each shift in speaker. Collaborative narrative styles were more common with over seven times as many collaborative codes recorded for all of the couples in total, compared to conflictual codes although couples with more conflictual codes also engaged in some collaborative interaction.

The speech of the collaborative couples mainly built on each other's narratives, with a high degree of 'confirmation' and 'confirmation-collaboration' codes and very little conflictual interaction. The couples displaying a conflictual style of narrative often disagreed or interrupted the spouse with a negative response and frequently continued talking without taking into account what their spouse had said previously (identified as continuation), indicating an implicit conflictual style. 'Non-response' codes did not occur frequently; hearing problems, common in older age, appeared to contribute to most of the non-response rather than this being intentional.

The extract below from Ted (stroke survivor) and Rita's transcript gives examples of both collaborative and conflictual codes. The couple are discussing Rita's retirement. At the beginning of the example Ted continues the narratives without reflecting on Rita's comment on their age difference but then they collaborate together to extend the storyline and build the narrative about the reason for Rita's retirement. When Rita brings up the topic of her pension Ted then questions Rita's comment that she was 'lucky' to get a good pension from the company and then the couple enter into a series of conflictual responses, explicitly disagreeing with each other about Rita's pension and the age at which she retired.

An extract from Ted and Rtia's transcript, coded using to Veroff et al's (1993) coding scheme

	R: He's only 4 months, well just over 4 months older than me.
Continuation	T: And you only packed up at the (company) because they moved.
Confirmation-collaboration	R: yeah because they moved. Otherwise I would have been there right until you know I had to retire but-
Confirmation-collaboration	T: She wasn't going to travel.
Confirmation	R: I wasn't going to travel.
	Interviewer: Where did they move?
Collaboration	R: I don't know, oh (building name).
	I: Oh (building name)
Collaboration	R: Blacksmith Road but I wouldn't go all that way.
	I: So they used to be here did they?

Confirmation- collaboration	<p>R: They used to be just here, well about ten minutes walk away from here.</p> <p>T: Tanton Street.</p>
Collaboration	<p>R: Tanton Street. There used to be a big building down there.</p> <p>T: It was *** publications.</p>
Continuation	<p>R: I used to leave here and ten minutes I was in work. It was easy, no travelling. But ur if I'd have gone over there it would have been too much for me so I said no I wouldn't do it so I just whats-a-name packed it in like. Well I didn't but they said to me, what do you want to do like and I said well, but I'm on a pension from them so whats-a-name, which is very good really to get a pension from them because I didn't expect it so I was lucky-</p> <p>T: You was paying in for it.</p>
Conflict	<p>R: what?</p> <p>T: The pension.</p>

Conflict	R: I wasn't there that long.
	T: You were still paying in for your pension.
Conflict	R: Yeah but I wasn't, I was only there for what, 5 and half years,
	6 years but I get a good pension now so that's it. I never paid in
Conflict	that amount what I get. I mean since I packed up when I was
	about 60, 60 odd.
	T: I think you was over 60.
Conflict	R: I wasn't 'cause they used to say to me haven't you got your
Conflict	bus pass. About 60 and um, that's long enough isn't it. That's 23
	isn't it, 23 years ago. So I'm sure I never paid in all that amount
	of pension (laughs). I wish I could go back to work, wish I could
	have them days back to work again. Because once you retire
	you get everything happen, you know, everything goes.

The conflictual responses at the end of the extract above is also an example of how couples would discuss and negotiate topics amongst themselves, using both conflictual and collaborative interaction, reflecting 'back stage' behaviour (Goffman, 1959), placing the interviewer in an observer role (Bjornholt and Farstad 2012).

I now examine couples' collaborative and conflictual narrative styles in more detail drawing on other examples from the joint interview data.

Collaborative narrative styles

Although there were elements of collaborative co-construction in all of the joint interviews, based on the general pattern of the narrative there were ten interviews that were collaborative in structure, overall. Two of the couples (Molly/ David, Patrick/ Betty) in particular appeared to be performing well-rehearsed narratives that may have been told before in different forms, to different audiences. These couples would sometimes say the same sentence at the same time, echo each other and finish off each other's sentences.

The following quote shows Molly, a stroke survivor, and her husband David engaging in a confirming and collaborating form of narrative, each one building on what the other has said, to continue the storyline about David's experience of taking the anticoagulant drug warfarin.

Molly: *Yeah we go (to the warfarin clinic) together.*

David: *It don't half alter your blood you know that warfarin. Didn't I just caught myself out there the other day.*

M: *He just knocked his arm.*

D: *Just a titchy little thing and it heals up, all better now, there's nothing the matter with it but it looks horrible. Yeah. I had a lump come up too didn't I, you want to hear another problem?*

M: *he had a lump in his jaw.... Never stopped bleeding.*

D: *.....And eventually they can't stop bleeding so I get them tablets, I got some tablets, they didn't stop it so James from the what was it?*

M: *From the warfarin (clinic)*

D: *From the warfarin, he phoned up some professor geezer and he said double it up but then we had another plan what we should have done in the first place, keep chewing on lumps of cloth to stop the bleeding. When I waking up in the morning and my tongue was like that*

M: *Yeah it was horrible.*

D: *Cor, oh my god, frighten you. I think we managed to sort it out ourself Molly didn't we (laughs).*

(Molly, aged 76, stroke survivor and David, aged 81, husband of stroke survivor)

The next extract shows Patrick and Betty engaging in a confirmation form of narrative. They repeat each other, with Betty providing prompts and Patrick requesting confirmation, working together to construct the narrative.

P: *And I've got them ear phones, what do you call them?*

B: *Hearing aid.*

P: *Hearing aid.*

B: *From (hospital).*

P: *I put them in. When I go in the main road, the traffic, oh, it's terrible.*

B: *You're not wearing them, are you?*

P: *I'm not wearing them, no, well.*

B: *You're not wearing them.*

(Patrick, stroke survivor, aged 85 and Betty, wife of stroke survivor, aged 83)

Couples who co-constructed collaborative narratives frequently used 'we' (discussed in more detail in Chapter Six). In the data extract below Penny talks about Jack's operation to treat Carpal tunnel syndrome (that caused pain in his hand) as if she too was undergoing the operation. Jack also uses 'we' when talking about a nurse visiting him at home.

P: *We did go up to the, I think it was *** (hospital), and we were seen and we was all set to do this operation. And then when everything was going through and we had to wait, that's when he had the stroke. And when I mentioned it to the stroke doctor, when he went up to the clinic, he said no he couldn't think of doing it after the stroke, he'd have to leave it. Nothing's really come back since. But that hand's got worse.*

J: *The week before last we had a nurse coming round and she took blood, took my blood test.*

(Jack, stroke survivor, aged 79, and Penny, wife of stroke survivor, aged 59)

In summary ten couples displayed generally collaborative patterns of interaction. These couples worked together to build co-constructed narratives that provided agreement and affirmation and continued each other's storylines. Their collaborative narrative style reinforced their co-presentation and identity as a couple, discussed further in the section on co-presentation of identity (see page 192). I now discuss the narrative styles of the remaining three couples.

Conflictual narrative styles

Three couples' co-constructed narratives displayed conflictual patterns. Although they also displayed elements of collaboration, they displayed the highest number of conflictual codes of all the couples. Two conflictual narratives were constructed by male stroke survivors and their wives (Richard/ Judy, Ted/ Rita). These couples reflected narrative patterns identified in previous research based on joint interviews with male stroke survivors and their wives who often engaged in 'competitive' storytelling, supplementing, correcting and contradicting the stories of their husbands (Manzo et al., 1995). The following quote shows Judy interrupting and continuing without reflecting on Richard's comments. She took the dominant role in the narrative by engaging in competitive storytelling, presenting herself as the narrator who will tell the 'correct' version of the story of her husband's stroke.

J: Well, what happened was, erm, he came, he used to go down to the pub every day, you know, to have a couple of pints, and he just come barging in one day and through the door and he said, 'I can't walk'. And he just got near

the chair and I had to grab him, he just fell to the floor nearly, and I just got him in a chair. So I called our doctor and she came out. She was a French doctor at the time, and she said, 'You've had a slight stroke Mr Finch.'

R: She sat there and said, 'You're having a stroke.'

J: Yes, well we know that Richard. I'm just giving her (the interviewer), I'm telling her exactly what happened. (Addressing the interviewer) Sorry, I'm not being rude to him, but he does this every time.

(Richard, aged 83, stroke survivor, and Judy, wife of stroke survivor, aged 67)

In the quote below Ted's wife, Rita, also engaged in competitive story telling about her own health problems, which she talked about in detail. Like Judy, the narrative style became conflictual when her husband interrupted, as she told him to 'hang on' so she could continue with her story. They also explicitly disagreed with each other when they discussed whether or not Rita had previously had tuberculosis.

R: I've had a gall bladder removed, I've had ulcer, I've had hernia, peritonitis, gangrene in the intestines, I've had all. I've had that done twice, haven't I, my intestines. Because when they done it, they done the operation, instead of putting the intestines back together like that, whoever done it put one on top of the other one.

T: They never had the antibiotics they got now.

R: Hang on (addressing husband). They put, when they fixed it they put it back they put one lot on top of the other like that so the food was going through and it was getting blocked so I got a blockage, what's called a

blockage of the bowels. So they had to take me in again, undo it all and stitch it up properly... I mean it's like TB, when they said I had TB. They cured that but it's come back again.

T: *You never had TB.*

R: *No I just said to the girl (interviewer) I didn't have TB.*

T: *They thought you had TB.*

R: *They thought I had TB.*

(Ted, stroke survivor, aged 84 and Rita, wife of stroke survivor, aged 83)

Judy and Rita were very keen to tell the story of their husbands' stroke from their own point of view in terms of the disruption it meant for their own lives as they had had to take on roles as full time carers, despite their own ill health. Although Judy was 16 years younger than her husband she also had health problems, including diabetes. Both husbands also had in common severely limited eyesight, unrelated to their stroke, and were both registered blind which appeared to place a high burden of care on their wives. It is possible that this could have changed the dynamic of the couple's relationship, reflected in the narratives in relation to the way in which both Judy and Rita talk about their caring role and how dependent their husbands were. At times the wives refer to their husbands as if they were children and discuss them almost as if they were not present, as illustrated by the extract below from Ted and Rita.

R: *I have to cut his food up for him and all that because he can't cut his food up properly and he can't see what's on the plate and that goes everywhere... He can't see the steps when he goes out like, you know. When he goes out*

he's got his stick, his white stick and that but, but I was out one afternoon, he'd gone across the shops on his own, you see so he can't be trusted.

T: I've gone across on the crossing.

R: That doesn't make any difference, whether you're on the crossing or not because you can't see... I tell him he's not to answer the door when I'm not here. So, but I think on the whole his life had completely changed, completely changed. He's completely changed now to what he was because I mean there's nothing in the home now that he can do because he can't see to do anything. He can't wash up or anything like that because he can't see. If he washes up I have to go back and do it again because it's not clean... He's flooded me out three times, he's flooded me out from the bathroom up here (upstairs). Ah! He leaves taps running and lights on. I have to go round of a night time to make sure lights and taps are turned off... He's got a terrible habit of going and knocking things all over the place.

(Ted, stroke survivor, aged 84 and Rita, wife of stroke survivor, aged 83)

However it is possible that to a certain extent the two couples' narratives reflect the style of interaction in their relationships more generally, with the wives tending to dominate narratives, regardless of their caring role, as this joke from Richard about his wife implies (and also provides an example of an implicit conflictual interaction).

R: (The stroke has) stopped him from going down the pub, which has spoilt him, you know, he hates it.

J: Someone down the pub said, 'I've just been up to your house, your wife has lost her voice.' So I had to leave to come home and enjoy it!

W: *He's being sarcastic now. There's nothing wrong with his brain, that's for sure!*

(Richard, stroke survivor, aged 83 and Judy, wife of stroke survivor, aged 67)

The third narrative displaying a conflictual style was from a female stroke survivor and her husband. Although Sarah had aphasia resulting in slow, slurred speech she took the dominant role in the narrative, engaging in semi-monologues (Morris, 2001), in contrast to her husband Nelson who engaged in minimal responses. This was reflected in a greater number of 'non-response' codes from Nelson and more 'continuation' from Sarah who sometimes appeared to be speaking about Nelson as if he were not present, as Rita and Judy also did. In this way their narrative differed from those of Ted/Rita and Richard/Judy as the conflictual interaction was less explicit.

N: *I was (in hospital) for 8 months.*

Interviewer: *8 months?*

S: *Yeah they still monitor him as well.*

I: *Because of the depression?*

S: *Yeah, why, because he was so sad when see me (after the stroke) he that say oh my god, the person who is taking care of me day and night, and he become like this. So he is going to. He say he is going to kill himself for that. I said no. Instead of me, looking at me suffering, I say that is not the way to help me, you make life worse for me.*

(Sarah, stroke survivor, aged 76, and Nelson, husband of stroke survivor, aged 77)

Co-constructing a collaborative narrative was not a priority for the three couples displaying a conflictual style as various health problems and disability experienced by both the stroke survivor and their spouse appeared to be making life very difficult for them at the time of the interview. Underlying tension and conflict between the couples affected the structure of their co-constructed narratives displaying themes of illness, disability and caring roles and responsibilities.

Based on a systematic and rigorous method to analyse interaction between couples in joint interviews, the present study has identified collaborative and conflictual narratives styles. This has furthered and extended previous findings from a small number of studies focusing on interaction style, as well as interview content, identifying largely collaborative narrative styles (Bjornholtand and Farstad 2014; Sakellariou, Boniface et al. 2013; Torge 2013; Morris 2001, Polak and Green, 2015). The present findings examining the collaborative narrative style based on a detailed and replicable analysis builds on types identified in previous studies. This includes the 'working it out together' style where couples talk between themselves to negotiate a narrative and the 'we' style based on couples constructing shared narratives (Morris, 2001) and similarly the 'we-ness' narrative style characterised by couples confirming each other's points (Torge, 2013).

The present findings have identified and examined conflictual patterns of interaction between couples, only discussed relatively briefly by the small number of previous studies focusing on interaction. For example some disagreements and contradictory interaction have been identified between couples (Torge 2013; Bjornholtand Farstad, 2014; Polak and Green, 2015).

In the present study two of the wives from the couples displaying conflictual narratives tended to dominate the narratives, reflecting the 'competitive' storytelling, supplementing, correcting and contradicting identified in relation to wives of stroke survivors' based on Conversation Analysis of interaction between 14 couples (Manzo et al. 1995). However the present study has shown that these findings have limited applicability to only two wives out of the 13 couples, with the present study identifying further collaborative narrative styles in relation to both male and female stroke survivors and their spouses. The three wives engaging in conflictual narratives could perhaps be regarded as 'stealing the scene' (Shakespeare, 1993) at times, to manage their husbands' 'performance' during the interview. However the concept of 'scene stealing' was developed in relation to interaction between the people with dementia and their informal carers, referring to the way in which informal carers dominated the narrative to promote the conversation as 'normal', whereas the present findings indicate that 'scene stealing' reflected the difficult circumstances of the couples and the tension between them, discussed further, later in this chapter (see page 202).

The next section brings together the analysis on the style of narratives, in terms of *how* people talk about and present events, and analysis on the content of narratives, in terms of *what* is said. Building on this analysis identifying couple's narrative styles, the content of interviews was also taken into account to develop further codes and ideas about the data, providing a further layer of analysis. This involved detailed readings of sequences of transcripts coded as conflictual and collaborative interaction based on Veroff et al.'s (1993) coding scheme, to examine the content of the transcript to identify themes of co-presentation in relation to narrative styles, providing a further layer of analysis. This differed from the thematic analysis carried out

for findings presented in Chapter Four as this focused on narrative themes of self-presentation rather than themes of co-presentation that couples presented together. Codes were developed and built on to identify types of co-presentation of identity underpinned by particular narrative styles see (Appendix H, page 357). Collaborative and conflictual styles of narrative underpinned three types of co-presentation of identity identified in relation to the content of the narratives, referred to as 'united couple', and 'positive' and 'frustrated' carers, to which I now turn.

Co-presentation of identity

'United couple'

Presentation as a 'united couple' was evident in aspects of most couples' narratives but emerged very clearly in the collaborative interaction between five couples (Molly/David, Gretel/Vas, Tom/Nora, Hilary/Adam, Tony/Cathy). Despite the stroke often initially causing great disruption to their lives, these couples presented themselves as morally competent, self-sufficient couples who had jointly adapted to varying levels of disability as a result of the stroke. Their narratives showed that together they were currently managing life with stroke as well as other illnesses and hardships, and often minimised the impact of the stroke. Their narrative style was largely collaborative, characterised by the frequent use of 'we' and by confirming and collaborating talk through repetition and overlapping to finish each other's sentences in ways that emphasised their partnership. One example is Molly and David's co-constructed narrative. After Molly's stroke David had to help her with aspects of personal care such as getting dressed and he took on more of the

household chores, despite his own heart condition and problems with his eyesight. However they presented themselves as a 'normal' couple who engaged in activities as other retired couples did. To continue the storyline each built on what the other had said, as can be seen in the extract below.

M: *There's a lot of people half our age who are worse off than us, aren't there, you know what I mean. And there's lot who've just won the lottery who are better off than us.*

D: *We are going on holiday in June, July. We're going with the-*

M: *Charity.*

D: ***** Charity*

M: *In a coach ride.*

D: *We're going to *** Bay*

M: **** Bay, yeah go down there. We'll take a few days out.*

D: *They take you out for couple days trips.*

(Molly, stroke survivor, aged 76 and David, husband of stroke survivor, aged 81)

In some cases 'united couples' described their relationship as strengthened through the shared experience of stroke. For example, Greta, a stroke survivor, described how she could only go out of their high rise flat if her husband (Vas) was with her due to her risk of falling. Rather than talking about being dependent on her husband she presented the two of them as 'a team' who were dependent on each other, demonstrating a sense of agency and autonomy as a couple. This extends findings from a case study of an

older couple whose identity as a couple, or 'we-ness', was strengthened because of their mutual dependence due to both spouses suffering ill health, including stroke (van Nes et al., 2009), indicating that this finding has applicability to a wider group of older stroke survivors and their spouses. Throughout their narrative Gretel and Vas' engaged together in a confirming and collaborating form of interaction, agreeing with one another and building on each other's narrative:

G: We have always been a loving and caring couple, I can say that without hesitation but obviously our relationship has changed because chores in the house I would do without thinking about it. I am restricted in doing so...

V: Now I've got to do it (laughs).

G: You don't have to, but you do it (laughs). So our relationship has deepened. No?

V: Oh absolutely.

G: We are more, as I said before we have always been close, very close and we are well known among friends and family, they say with a couple like you, one doesn't fight very often... it was destiny that I came from Germany and Vas came from Cyprus, we met and lived happily, happily ever after... Both of us we are a team. We've always been but since I had the stroke-

V: We've always been, now it's more, because she needs me. We are more close than ever.

(Gretel, aged 78, stroke survivor and Vas, aged 80)

The co-presentation of a 'united couple' builds on findings from another case study based on joint interviews with a middle aged couple prior to the husband's coronary artery bypass surgery (Gerhardt, 1991). The couple strived together to present a 'unified front' as an honest hard working couple, creating an image of their relationship as competent and 'normal', despite experiencing chronic illness and financial hardship. Findings from the present study indicate that the notion of couples constructing a 'unified front' together through their joint narrative has a wider application to couples of advanced older age and participants with a health condition of a different nature, and also to couples where both spouses are suffering from ill health.

It is important to acknowledge that there were variations among co-presentations as a 'united couple'. Tony and Cathy's narrative differed markedly in structure to the others as, although Tony had made a good physical recovery from his stroke, his aphasia meant he spoke in a slow, stilted manner, sometimes stuttering, and had some difficulty finding the correct word (expressive dysphasia). Aphasia can impose critical limitations in the creation of narratives (Shadden and Hagstrom, 2007). As their narrative progressed Cathy began to take a more dominant role by prompting, correcting or answering for Tony and finishing his sentences. Tony would also ask Cathy for confirmation or support to continue the storyline, shown here in the context of his recounting the history of his stroke:

T: I, we was on the boat, hh and um, no I had heart attack on the boat and I got to New York and they took me off the boat into the hospital and they fitted me with a pacemaker and it's, how many days after?

C: *It was about four days after you had a pacemaker put in, he had the first stroke....*

T: *Apart from the s, speech, um, that's all the result of the stroke, uh I don't*

C: *Yeah I mean obviously you're not as agile now as what you was before.*

T: *Huh now and again I get, um, leg, leg, left leg seelsa bit funny at times but ur I get about on that.*

C: *Not your left leg, your right leg.*

T: *Uh Right leg.*

C: *Because it was all down the right side.*

T: *Right leg.*

C: *where it was affected, yeah, yeah.*

T: *Sometimes it feels a bit funny but apart from that. A, a all er the troubles that I uh had is the breathing problems.*

C: *He has, he's made a fantastic recovery. You know, as I say, no one thought he was going to come through it, even the doctors was so surprised.*

(Tony, stroke survivor, aged 75 and Cathy, aged 74)

Collaboratively the couple sought to minimise the impact of Tony's aphasia by using humour, enabling them to display an image of a 'normal' united couple. For example Cathy joked about her own hearing problems saying, 'he can't get his words out and I can't hear, we're a pair well matched!'. Through their collaborative narrative, Cathy was minimising Tony's speech difficulties, thereby minimising his failed every day performances and supporting his presentation of self (Goffman 1959). This can be regarded as

Cathy engaging in a process of 'identity validation' to support Tony's reconstruction of identity, identified as an important role played by wives of male coronary patients, aged 30-70 (Corbin and Strauss, 1987). Findings from the present study indicate that this process also applies to spouses in an older age group in relation to stroke, providing an analysis of how couples engage in or 'perform' (Goffman, 1959) 'identity validation' together through their co-constructed narratives, an aspect not focused on by Corbin and Strauss (1987).

Although Cathy assumed a dominant role in the narrative she appeared to use this to construct a socially acceptable presentation as a 'united couple', with Tony actively collaborating and inviting Cathy to take this role through his requests for confirmation from her at different points throughout the narrative. Therefore I argue that this could be regarded as forming 'scene support' rather than Shakespeare's (1993) notion of 'scene stealing' referring to the way in which informal carers dominated interaction in joint interviews to manage the 'spoiled performances' of people with dementia. Tony and Cathy's style of narrative is similar to the 'balancing act' described in relation to one couple, where the husband had slurred speech and the wife supported this narrative, in a joint interview study of older couples where both had disabilities (Torge, 2013). This narrative form did not occur in the co-constructed narratives of the other two participants with aphasia, possibly because they did not experience problems with word-finding as Tony did, as well as reflecting differences in individual personality.

The co-presentation of a 'united couple' displayed couples as interdependent partners, working together to construct a shared couple identity, strongly

linked to their collaborative narrative style. I now discuss the co-presentations relating to carer relationships, where the caring role of the spouses and dependency of stroke survivors emerged as more prominent in the co-presentations.

Carer relationships: 'Positive' and 'Frustrated' carers

As an unprompted part of their narrative all couples discussed the issue of one spouse caring for the other following their stroke. However the spouse's role as carer was more prominent in the co-presentations of eight couples (Jack/Penny, Patrick/Betty, Ted/Rita, Sarah/Nelson, Richard/Judy, Grace/Simon, Eric/Irene, Helen/ John). The co-presentation of a 'positive' carer relationship was linked to collaborative narrative styles whereas the 'frustrated' carer relationship was strongly linked to conflictual narratives styles. These two types of co-presentation will be discussed in turn.

Jack and Penny engaged together in a confirming-collaborative narrative to present a 'positive' carer relationship, portraying themselves as a self-reliant couple, with Penny willingly caring for Jack who had very limited mobility and required the use of a walking frame and wheelchair. Penny was 20 years younger than Jack and in much better health which may have meant that she experienced the caring role as less of strain than other spouses who were older and in poorer health, discussed further below. Together Jack and Penny presented Penny as a 'positive' carer with Jack describing how well he was looked after and Penny emphasising that it would be difficult to seek assistance from a paid carer due to Jack's stubbornness, implying that she was the best person to care for him. This was supported by Jack who emphasised Penny's 'natural' role as his carer:

J: Penny's be, been brilliant... In hospital I didn't like them cleaning me and washing me... If the wife's doing it, I mean, we've been together alotta of years and it seems more of a natural thing. But to have a stranger doing it,

it's, to me that weren't on... The thing is I've always been a very, very stubborn person.

P: Oh yes, very stubborn..... Well I know basically how, what he likes, what he don't like, you know, and I'm here all the time.

J: She knows how moany I can be.

P: Oh yes, I don't think a carer could take it, you know. They'd be running away (laughs).

J: She lays the law down...but really when I sort of think about it, I, she's right.

(Jack, stroke survivor, aged 79, and Penny, aged 59)

This previous extract portrays wives as 'natural' carers, reflecting social expectations that within families, informal caring roles will be taken on by females. It is possible that the notion of gendered caring as 'natural' offered ontological security (Giddens, 1991) to both Penny and Jack, enabling them to maintain a sense of stability by continuing family life and relying on family identities (Gregory 2005). However husbands were also presented as 'positive' carers in the narratives of Helen/ John and Grace/ Simon, as illustrated by following quote:

G: Not one of my children would ever do me, open their hearts to me as how Simon... He wash, he cook, he iron, he clean, he do everything believe me... He's not well as well so I don't want to see him lay down 'cause if he lay down I will suffer.

S: ... I'm not too well really...I've got this prostate (problem)...life have to continue.

G:... He have to do everything, he have to put my clothes on for me. So it is really bad. Really, he, he wash me. So I am really bad. I'm not hiding it and I can't, God give me him for a reason.

(Grace, stroke survivor, aged 78 and Simon, aged 75)

Other spouses talked about their caring responsibilities with a sense of pride. The following two quotations show that Betty and Judy presented the words of health care professionals as a narrative device to legitimate and provide support to their positive presentations as carers. This supports their construction of identity as dutiful caring wives, demonstrating that they are rising to the challenge of the caring role, fulfilling their marital duty despite personal sacrifices.

*You had that pneumonia, I nursed him. Doctor *** said to me, you know, 'you've saved the hospital hundreds of pounds.' And I said, 'Why?' And he said, 'you've nursed your husband in the right and proper way.' Which I did, didn't I?*

(Betty, wife of stroke survivor, aged 83)

J: I've been a good nurse, haven't I Richard?

R: Pardon?

J: I've been a good nurse.

R: Hmm.

J: Yes the nurse at (hospital), she said to me, because I think she realised that I was a lot younger, she said, 'You know what,' she said, 'I really admire you,' she said, 'The way you look after your husband,'.

(Richard, stroke survivor, aged 83 and Judy, wife of stroke survivor, aged 67)

However whereas Judy described her 'positive' caring role, this was accompanied by aspects of the dutiful but 'frustrated' carer that also characterised the account given by Rita, indicating that couples' narratives could display aspects of the 'positive' carer type of co-presentation as well as aspects of the 'frustrated' carer type. Judy and Rita were both very keen to tell their own story of their husband's stroke in terms of the disruption it meant for their own lives due to the high level of care their husbands required. This was primarily due to a lack of mobility following the stroke which occurred two and half years (Ted/ Rita) and three years (Richard/ Judy) prior to the interview, but also both husbands' had severely limited eyesight that had led

them to be registered as blind. The extracts below illustrate the wives' frustration with their situation and their husbands, with their narratives underpinned by a mainly conflictual style.

J: He can't walk down the stairs, he's, because of his breathing, his walking has got very poor... I have to – he can't even wash his self, I wash him down every day. Give him a wash. This is what I want, I want a shower to give him a shower. (The council) said it's pointless putting a shower in here because you're on the move and they won't do it.

R: We won't be moving, I doubt it, for ages.

J: Oh Richard, we're down to move, so they won't do nothing about it.

R: Yes, we're down to move.

J: No, you know, they just won't do it, because we're on the move.

R: Don't tell them we're on the move, then they might do it.

J: Well they know we're moving. Oh God. It's frustrating for me getting through to him.

(Richard, stroke survivor, aged 83 and Judy, wife of stroke survivor, aged 67)

Similarly Rita who presented herself as a dutiful but 'frustrated' carer took a dominant role in her narrative with Ted:

R: I've had 'eart attack myself, well I've had three stents put in as well you see so, obviously I can't, when he falls I can't pick him up. And I've also got arthritis all over me back and I just can't whatsaname so I can't cope with

him....I have to cut his food up for 'im and 'cause, you know, he can't cut his food up properly and he can't see what's on the plate and that goes everywhere... He can't see the steps when he goes out like, you know. When he goes out he's got his stick, his white stick and that but but I was out one afternoon, he'd gone across the shops on his own, you see so he can't be trusted.

T: I've gone across to the shop on the crossing.

R: That doesn't make any difference, whether you're on the crossing or not because you can't see... I tell him he's not to answer the door when I'm not here. So but I think on the whole his life has completely changed.

(Ted, stroke survivor, aged 84 and Rita, aged 83)

The quote above illustrates the challenges of spousal caring when both spouses are suffering from ill health. Both Judy and Rita had various health conditions including diabetes (Judy) and a heart condition and arthritis (Rita) which meant they experienced difficulties caring for their husbands who were very dependent on them, which emerged during their presentations as 'frustrated' carer, underpinned by a mainly conflictual style of interaction.

A further variant of the carer relationship that deviates from the 'positive' or 'frustrated' carer co-presentations was provided by Sarah and Nelson. This narrative focused on Sarah's previous role in caring for Nelson 'day and night' during their 60 years of marriage, and Nelson's inability to act as a carer to Sarah after her stroke, due to his depression and mental health problems. Sarah was left severely disabled and housebound after her stroke. The couple talked about Nelson's severe depression happening as a direct result

of Sarah's stroke and how he spent eight months in a mental health unit from the week she was discharged from the stroke unit, meaning they were living apart during all of that time. Sarah and Nelson seemed to have both experienced Sarah's stroke as a major biographical disruption to Sarah's role as a dutiful caring wife and to their marital relationship. Although Sarah had slurred speech she took the dominant role in the narrative, talking about how she coped with disability and how she relied on care workers and her children. She talked about how hard this made life for her and how she had to be strong to cope and had to 'be a man', possibly implying that her husband had not acted as she expected a man to. This is in strong contrast to the collaborative accounts presented by other couples such as Jack and Penny and Greta and Vas, who present a 'united front', talking about how they have coped with the stroke together as a couple. However Sarah's narrative presents herself as the one who is coping with her disability, almost comparing herself to her husband as a way to illustrate how well she has coped. She also talks about the value of their marriage vows presenting herself as someone who is taking the moral high ground by 'taking her husband back'.

He was so sad when he see me (after the stroke) he say oh my god, the person who is taking care of me day and night, and she become like this. So he is going to, he say he is going to kill himself for that. I said no, that is not the way to help me, you make life worse for me... Without him it's hard for me. We are totally on top of each other for 60 years and I go (to hospital) for 6 weeks with this (stroke), because I'm in the hospital and when I come out from the hospital the first week he is gone again (for 8 months). What a life. But I have to be a man. Be strong for myself and my children... Finally, he say no he's going home (from hospital)... (I was asked) 'Do you want to take him back?' I say well, he's my husband, with my door open I welcome him

with all my heart... (the marriage vows) didn't say for better I stay, for worse I run away.

(Sarah, stroke survivor, aged 76, and Nelson, husband of stroke survivor, aged 77)

Tension and conflict between Ted/Rita, Richard/Judy and Sarah/Nelson emerged in the conflictual structure of their narratives that underpinned their co-presentations, largely dominated by themes of stroke and other ill health, profound disability and the need for a high level of care. This indicates the strong link between couples' types of co-presentations and the narratives styles they engaged in. Various health problems experienced by both the stroke survivor and their spouse appeared to be making their lives very difficult. The couples' conflictual narratives therefore were likely to be at least partly driven by the practical realities and hardships they were experiencing in coping with stroke and other ill health at the time of the interview and may have been influenced by the relative recency of the stroke, with interviews at 1-3 years post stroke.

Discussion

In addressing the research question ‘how do older couples present themselves following a stroke?’ findings extend notions of how illness is ‘lived’ in terms of older couples’ interpersonal relationships and daily lives. Three main types of co-presentation of identity emerged from analysis of both the content of narratives, ie. *what* is said, and style of narrative, ie. *how* people talk about and present events. ‘United couple’ displayed couples as partners pulling together to cope with the stroke and other disabilities, strongly underpinned by the couple’s collaborative interaction. ‘Positive’ carer presentations were similarly underpinned by a collaborative style of narrative as part of a display of self-reliance as a couple, with both a ‘united couple’ and ‘positive’ carer characterised by a stoic attitude. Although many of these stroke survivors were physically dependent on their spouse, thus lacking personal autonomy, their co-presentation demonstrated a sense of agency and autonomy as a couple. These couples engaged in co-presentations as partners rather than as carers and patients, with most spouses unlikely to view themselves as ‘carers’. It is important to acknowledge, however, that these couples may have underemphasised conflicts and spousal burden during joint interviews (Torge, 2013). In contrast couples who engaged in ‘frustrated’ carer presentations, underpinned by conflictual interaction, tended to emphasise spousal burden which may reflect both the prior marital relationship and the practical realities and hardships experienced by older spousal carers in coping both with their own ill health and their spouse’s disability.

Narratives are likely to vary according to age, class and gender reflecting couples' particular life experiences and circumstances. In terms of class the findings reflect narratives of couples from predominantly working class backgrounds. However two of the couples were from a middle class background, based on previous occupations. In terms of narrative style these two couples were in line with the other couples who engaged in a mainly collaborative style, displaying elements of the united couple co-presentation (Hilary/Adam) and positive carer co-presentation (Helen/ John).

With regard to gender, husbands and wives engaged in similar collaborative or conflictual forms of interaction, which is discussed in more detail in Chapter Six. During the three mainly conflictual narratives the wives tended to dominate, which may have reflected the general nature of these couples' marital relationships in which the wives took a dominant role in conversational interaction with their husbands. However it is likely that their relationships changed over time and have been shaped by the experience of the stroke and other ill health, with the nature of the marital relationship known to be influenced by illness and disability (Walker and Luszcz 2009). This is suggested particularly by the way in which both Judy's and Rita's accounts tended to portray themselves as 'frustrated' carers coping with a high burden of care and to infantilise their husbands who were both registered as blind. Rather than presenting themselves as partners in a 'united couple' Judy and Rita both presented themselves in terms of a carer/ patient relationship with their husbands, reflecting the change in their marital relationships and spousal roles. It is possible that over time these three couples engaging in mainly conflictual narratives may adapt to the changes in circumstances and spousal roles and perhaps engage in narratives that are more collaborative in style. However more time living and coping with stroke in the context of

the declining health of both spouses may perhaps lead to greater challenges and tensions that may emerge through narratives that are even more conflictual in style.

With regard to age, the findings reflect the narratives of older couples, with the majority of couples aged 75-85 years as most spouses were a similar age to each other. There were two exceptions to this; Penny who was 20 years younger than stroke survivor Jack, and Judy who was 15 years younger than stroke survivor Richard. Both wives were carers for their husbands who were both disabled with very limited mobility. However Penny engaged in a 'positive' carer presentation underpinned by collaborative interaction whereas Judy engaged in a largely 'frustrated' carer presentation underpinned by conflictual interaction. This was partly due to Judy's own ill health as she had diabetes, and due to unsuitable housing that was not meeting the couples' needs (as discussed in Chapter Four), but perhaps also due to the general nature of interaction within the marital relationship. Therefore, as discussed, Richard and Judy's narrative showed more similarities with Ted and Rita's who were both in their mid-eighties. Although Judy was 15 years younger than Rita, they were both coping with a high burden of care for husbands who had both had significant disability after their stroke and both had limited eyesight, despite their own ill health. Therefore the health of spousal carers was more important than age in terms of couples' narrative style and content.

The method of joint interviews and the novel approach to analysis has not only enabled a focus on couple's co-presentations in relation to *what* is said in terms of the content of talk but has also analysed *how* people talk about

and present events through different forms of narrative styles. This has enabled an in-depth understanding of older couples' relationships and how they adjusted and accommodated to the considerable impacts on their lives of stroke and other chronic illness and disabilities. For example, it was notable that stroke survivors were often able to demonstrate agency through drawing on their autonomy as a couple, despite being physically dependent on their spouse. The findings also highlight the complexities of spousal caring amongst older people, especially as they are more likely to rely on a spouse for social, emotional and physical support as more couples survive into old age (Pickard et al, 2012). As couples age wider social support networks shrink and they are more likely to become socially isolated, identified by Charmaz (1983) as one of four sources of loss of self experienced by chronically ill people. In light of this some couples are perhaps more likely to turn to each other for support in constructing and validating particular identities as they age, such as the 'united couple', whereas other couples may experience chronic illness and high burdens of care as especially challenging, particularly within the context of shrinking social support networks, and so are perhaps less likely to engage in supportive and collaborative narratives to construct and validate each other's identities.

This chapter has presented findings based on two layers of analysis of joint interview data focusing on both the content of the narratives and the style of interaction between couples. The next chapter brings together the data from the individual and joint interviews, extending this novel approach to analysis by drawing on a sociolinguistic approach.

Chapter 6. Findings: Language and narrative construction

Introduction

This chapter examines the sociolinguistic construction of all biographical narrative interviews in relation to gender, interview context (individual and joint) and narrative type. As discussed in Chapter Two, language and social interaction in everyday life are essential parts of the construction of self-identity according to Goffman (1959) and a symbolic interactionist perspective more generally. This notion has been very influential in the sociolinguistic approach to the study of language in everyday life concerned with the social and cultural aspects and functions of language. Within a feminist framework, sociolinguists have been increasingly interested in the performance of gender in everyday interaction, arguing that gender roles in society are reflected in the everyday use of language but also that the relationship is two-way, with everyday language influencing the way in which gender identities are constructed. One novel approach to exploring illness narratives through a focus on language and the influence of gender is the comparative keyword analysis method based on a sociolinguistic perspective (Seale, Ziebland et al. 2006). Comparative keyword analysis is an inductive approach using computer software to compare bodies of spoken text.

As discussed in Chapter Two, there is little sociolinguistic work focusing on both gender and older age, particularly in relation to older people who are frail and in poorer health and therefore more marginalised. There is also a lack of research using joint interviews in a health context. Only one study has been identified that has conducted a systematic comparison of individual and joint interviews (Seale and Charteris-Black 2008), although one major

limitation is that the study does not discuss age and the impact this may have on findings. As discussed in Chapter Two, old age is an important focus for health and social care professionals and policy-makers as the population is ageing and increasing numbers of older people are living and coping with chronic illness, and are often living in interdependent spousal relationships. A systematic and rigorous sociolinguistic analysis will add a further layer to the previous analysis focusing on stroke survivor's narrative themes of self-presentation, couples' narrative styles and couple's co-presentations. Analysis of the content, interaction style and language of biographical narrative interview data will contribute to an understanding of the impact of stroke on individual and couple identities and relationships and how people manage this, which will inevitably affect their health and social care needs and use of services.

In this Chapter I report on a systematic comparison of individual and joint interviews with older stroke survivors and their spouses based on a sociolinguistic approach. This consists of a novel approach to analysis, building on the comparative keyword analysis techniques developed by Seale, Ziebland et al. (2006), as detailed in Chapter Three (see page 84), and incorporating the coding frame developed by Veroff et al (1993), also detailed in Chapter Three (see page 81). The specific steps of the comparative keyword analysis are presented in Chapter Three (see page 86). The sample of stroke survivors are men and women aged 75 and over, from mainly working class backgrounds living in inner city areas (see table 3, page 91). To address the following research questions, analysis focused on differences in narrative construction according to gender, interview context (ie. individual or joint), status as a stroke survivor or spouse, and narrative type;

Research question:

In what ways do older couples engage in the co-construction of narratives to make sense of the stroke?

Sub questions

- In individual and joint interviews does the amount participants speak and how often differ according to gender?
- In individual and joint interviews does talk about personal experiences and shared experiences differ according to gender?
- In the joint interviews is there a difference in the way in which stroke survivors and spouses participate in the narrative?
- In the joint interviews, are there gender differences in participation in the narrative according to narrative type (drawing on Veroff et al.'s (1993) coding)?

Findings

Fourteen individual interviews were carried out with stroke survivors (eight women, six men) and 13 joint interviews were carried out with stroke survivors and spouses (six female stroke survivors and their husbands and seven male stroke survivors and their wives). First, findings from the analysis of individual interviews are presented in relation to gender and talk about personal and shared experiences. Second, findings from the analysis of joint interviews are presented, examining the following: comparisons with individual

interviews; gender and talk about personal and shared experiences; stroke survivors and spouses' participation; and gender and narrative type. This is followed by a general discussion of the findings from the comparative keyword analysis. Selected excerpts from transcripts are presented throughout to illustrate findings.

Individual Interviews

This section gives a brief overview of the number of words spoken and turns taken during the individual interviews in relation to gender. Overall, male stroke survivors spoke more words than female stroke survivors and took more turns.

Individual interviews lasted between 30-102 minutes, with a mean of 61 minutes (see table 4, page 216). The range of number of words spoken by participants in the individual interviews was wide, with Rose speaking the least (2287 words) and Ethel speaking the most (12273 words). Rose spoke fewer words because she became upset when talking about her stroke and the events surrounding it as it had happened only one week after her daughter passed away unexpectedly. She therefore took a short break during the interview and when the interview resumed talked more about the practical issues of the stroke event, her experience in hospital and her current health and mobility, rather than continuing to focus on a detailed account of the biographical events surrounding the stroke. In contrast Ethel gave a very detailed account of her stroke and the events leading up to her stroke in relation to her housing and her experience of antisocial behaviour on her estate and the severe financial problems she had experienced after her

stroke. She appeared to be taking the opportunity of the interview to express some of her anger and frustration over these experiences that were currently very significant in her life.

Martha had mild aphasia, speaking slowly and carefully, mixing her words up at times. This was reflected in her interview lasting longer than the mean average with fewer words spoken than the mean average. Paul also had mild aphasia, stuttering at times. His interview was one of the shortest in length, with one of the fewest number of words spoken.

Table 4. Length of interviews and number of words spoken by participants in individual interviews

<i>Individual Interviews (ID number)</i>	<i>Participants (N= 14)</i>	<i>Length of time (mins)</i>	<i>Number of words spoken by participant</i>	<i>Percentage of total words spoken by interviewer</i>
1	Rose	62	2287	15.14%
2	Bob	57	7236	5.46%
3	Mary	73	6771	6.24%
5	Tim	50	9742	3.42%
8	Leonard	30	1407	25.22%
9	Paul	32	2858	15.29%
12	Delia	74	4585	2.11%
14	Alfred	65	9468	6.23%
20	Joan	51	7560	4.72%
26	Martha	76	4128	15.15%
27	Gloria	78	3991	20.36%
28	Ethel	102	11273	7.6%
31	Derek	46	4851	12.07%
33	Sheila	40	4277	14.81%
<i>Mean</i>	-	61	5745	-
<i>Median</i>	-	59.5	4718	-
<i>Range</i>	-	30- 102	1407- 11273	2.11- 20.36%

In individual interviews, on average men spoke more words than women and took more turns (see table 5, page 217). This differs from previous findings

that women spoke more words and took more turns in individual interviews on different health related topics with participants from a range of ages (Seale, Charteris Black et al. 2008) and findings that women from a range of ages spoke more words in individual interviews on the experience of cancer and older men in particular spoke the least number of words (Seale and Charteris-Black 2008). It is possible that one explanation for men taking slightly more turns is because I, as the interviewer, asked them more probing questions as they were perhaps less likely to engage in more detailed narratives than the women.

Table 5. Mean number of turns and words in individual interviews by gender

	Men (n= 6)	Women (n= 8)	Interviewer
Mean no. of turns	74	71	72
Median no. of turns	72	68	72
Range of no. of turns	47-108	13-102	13-141
Median no. of words	8469	4431	456
Mean no. of words	6831	5609	557
Range of no. of words	5518-10244	2714-12404	99-1015

In the present study all eight of the female participants in individual interviews lived alone and six of these were widows. Four of the six men interviewed individually lived alone and four of these were widowers. It is possible that men spoke more than women when given the opportunity to talk about their stroke and other significant experiences in their life because they had less family and friends to talk to. Although all of the women lived alone it is likely that they had more contact with friends and relatives as women are more likely to have wider social support networks than men in old age (Arber and Ginn 2005).

Below is an example from an individual interview with Derek who appeared to be lonely and appreciated the opportunity to talk about his wife during the interview. Although his wife passed away ten years ago he talked about how he missed her and how frustrated he felt as he wanted an opportunity to talk about her to remember her but felt other people avoided this as they felt awkward.

*(My wife passed away) going on ten years. Yes St Valentine's bloody day.... But the bit that annoys me more than anything is people treat you like an idiot. Not intentionally, **but they talk to me, but they won't talk about her. It's as if they're trying to say she never existed. I know bloody well she did. And that annoys me....** (She had) emphysema... Oh she was desperate, really was. She would sit here and she would put two words together and she would be going... (laboured breathing sounds)... that is the bit that got me more than anything. There's nothing you can do, you feel like, you know, I don't know, you feel like strangling yourself, you're so bloody useless.*
(Derek, aged 77)

In summary, male stroke survivors engaged in narratives using notably more words, on average, than female stroke survivors, contradicting findings from previous studies. One possible explanation is that male stroke survivors in the present study were older and in poorer health than men in previous studies of this nature (Seale, Charteris-Black et al. 2008, Seale and Charteris-Black 2008) and therefore were more socially isolated with smaller social support networks compared to women, and therefore had less opportunity to talk to other people. This indicates the possible influences of older age, social isolation and loneliness on the way people engage in the construction of illness narratives.

Gender and talk about personal and shared experiences in individual interviews

Following the comparative keyword approach (Seale, Ziebland et al. 2006), use of singular pronouns (I, me, my, mine) indicates talk about personal experiences and use of plural pronouns (we, we're, we've, our, us) indicates talk about shared experiences. Overall, men spoke more about their personal and shared experiences than women during individual interviews.

Men talked more about their personal experiences than women, based on a higher use of singular pronouns according to the mean and median average (see table 6, below). This contradicts previous findings that women were more likely to speak about their personal experiences during individual interviews (Seale, Ziebland et al. 2006; Seale, Charteris-Black et al. 2008).

Table 6. Mean number of singular and plural pronouns used in individual interviews by gender

	Men (n= 6)	Women (n= 8)
Mean no. of singular pronouns	657	470
Range of number of singular pronouns	299-1087	243-804
Median no. of singular pronouns	544	395
Mean no. of plural pronouns	129	48
Median no. of plural pronouns	42	18
Range of number of plural pronouns	4-425	4-56

The following is an example of talk about personal experience (use of 'I', 'me') by a male stroke survivor in an individual interview, illustrating the experience of social isolation as a result of disability following stroke:

I got used to now being at home, although these four walls here are all I ever see. Sometimes I put the tele on and you get fed up of that, you know. Um Angie (neighbour) downstairs brings me a paper about, usually about 11 or 12 o'clock in the morning and um so I'm just sitting here all day really, not much to do.

(Bob, aged 87)

The following is an example of talk about personal experience (use of 'I', 'me' 'my') by one of the two married male stroke survivors participating in individual interviews, illustrating changes in spousal roles within the marital relationship due to disability following stroke:

I know the frustration hasn't helped our relationship because I hadn't realised that I think it must depend on your partner and your family, I think there is a degree of resentment, you know. My wife says, 'Well why did you have to have (a stroke)?' because you're not doing the things that you could do or used to. It may be me, it may be just something that I'm picking up that's not there, but it shows itself, I think, in many ways, where I can't do things like I used to.

(Tim, aged 75, married)

In the quote above, when Tim states 'I think it must depend on *your* partner and *your* family' he is inadvertently referring to 'my partner' and 'my family'. This indicates an indirect strategy that aimed to distance the speaker from

the experience, as if it were happening to someone else. This strategy perhaps makes it easier to introduce very personal topics during the interview, in this instance about tensions in the marital relationship after stroke. This indicates an external perspective on illness experience by speaking in a generalised way and avoiding the use of first person pronouns, a strategy identified in relation to men from a range of ages participating in interviews on the experience of a wide range of illnesses (Charteris-Black and Seale 2009).

Men also used more plural pronouns than women in the individual interviews indicating that they talked more about shared experiences (see table 6, page 221). Even though four of the male individual participants had been widowed it is important to note that they talked about their spouses and previous shared experiences. Below is an example of the use of 'we' by Derek, referring to his late wife:

*I suppose **we** had a good life, **we** both enjoyed ourselves. Didn't do a lot but **we** enjoyed ourselves. She was happy with me and I was happy with her.*

(Derek, aged 77, widower)

In summary, male stroke survivors spoke more about their personal and shared experiences than female stroke survivors during individual interviews. Although this is partly likely to reflect the higher number of words they spoke overall, the mean average number of singular and plural pronouns spoken as a percentage of all words spoken were still slightly higher for men (for men: singular pronouns made up 10% and plural pronouns 2% of mean total words; for women singular pronouns made up 8%, plural pronouns 1% of mean total words). This indicates that previous findings that men were more likely to talk

about shared experiences in individual interviews compared to women (Seale, Charteris-Black et al. 2008) extends to older age groups. However present findings contradict previous findings that women spoke more about personal experiences in individual interviews (Seale, Ziebland et al. 2006; Seale, Charteris-Black et al. 2008). Again, this supports the possible explanation that male stroke survivors in the present study were older and in poorer health than men in previous samples and therefore had less social contact than the female stroke survivors and so took the opportunity of the interview to engage in self-presentations drawing on their own experiences as well as shared experiences with others. The present findings indicate the importance of older age and ill health in influencing the different ways in which men and women engage in narratives focusing on the experience of stroke.

The next section discusses findings from the joint interviews and makes comparisons with the individual interviews.

Joint Interviews

Overall, in individual interviews men took more turns than women and spoke more words but in joint interviews women were more likely to dominate, speaking more words and taking more turns.

Based on the joint interview data with stroke survivors and their spouses, the mean length of interview was 55 minutes, with a range of 42-78 minutes compared to 61 minutes for the individual interviews, and a range of 30-102 minutes (see table 5, page 217 and table 7, page 227). It could perhaps be expected that joint interviews would last longer than individual interviews due to two people both participating in the narrative. However ten of the 14 individual participants had been widowed and widowhood has been consistently linked to the experiences of loneliness and social isolation (Victor et al., 2000) therefore this could be one possible explanation for the individual interviews lasting slightly longer as participants may have taken the opportunity to talk about their stroke and other aspects of their life in an interview. Although I did not ask participants specifically about loneliness, in individual interviews two men and four women talked explicitly and implicitly about experiencing loneliness, mainly due to widowhood (see Chapter Four, page 116).

For the joint interviews the total number of words spoken by both participants had a wide range from 1772 to 11623 with a mean of 6380 words (see table 8, page 228). Table 8 shows that the number of words spoken does not necessarily correlate with the length of the interview, indicating that participants speak at different rates. This may be partly accounted for by participants with aphasia. Sarah, Tony, and Tom were stroke survivors with

aphasia and fewer words were spoken during these interviews compared to the mean.

The couples who spoke the least amount of words during joint interviews were Grace/ Simon and Helen/ John. Both Grace and Helen appeared to be in poor health and discomfort due to the stroke and other chronic conditions and both were wheelchair users. Therefore it was likely that it was more physically challenging for them to participate in the interview and indeed both seemed to become fatigued towards the end of the interview.

The joint interviews where couples spoke the most words were with Ted/ Rita and Jack/ Penny. Rita spoke over 70% of words in the joint interview with Ted, speaking at length about the difficulties of her caring responsibilities due to her own ill health (as discussed in Chapter Five, page 202). In contrast both Jack and Penny spoke a more equal share of words during their interview, going back and forth between each other, indicated by a high amount of turn taking.

Table 7. Length of interviews and number of words spoken by participants in joint interviews

<i>Joint interviews (ID number)</i>	<i>Participants (n=26) (stroke survivor in bold)</i>	<i>Length of time (mins)</i>	<i>Number of words spoken by both participants</i>	<i>Percentage of total words spoken by interviewer</i>
11	Patrick Betty	62	7968	16.53%
13	Jack Penny	65	11502	4.29%
15	Molly David	62	7744	12.64%
16	Ted Rita	78	11623	5.11%
17	Sarah Nelson	48	4029	23.13%
18	Helen John	45	1740	16.90%
19	Tony Cathy	44	4903	7.53%
22	Richard Judy	61	8949	9.23%
23	Hilary Adam	44	3026	11.80%
24	Grace Simon	42	1776	17.65%
29	Gretal Vas	49	5395	7.99%
30	Tom Nora	52	3175	10.77%
32	Eric Irene	68	11111	10.93%
<i>Mean</i>		55	6380	11.93%
<i>Median</i>		49	5395	-
<i>Range</i>		41-78	1772 to 11623	-

Men and women took more turns in joint interviews than they did in individual interviews which is to be expected as there was one more person to take

turns with compared to the individual interviews (see table 6, page 221 and table 8, below).

Table 8. Mean number of turns and words in joint interviews by gender

	Men (n= 13)	Women (n= 13)	Interviewer
Mean no. of turns	123	145	68
Median no. of turns	101	121	40
Range of no. of turns	32-341	35-354	29-180
Mean no. of words	1829	4545	754
Median no. of words	1359	3568	595
Range of no. of words	384-4764	640-9753	381-1578

In joint interviews women spoke more than twice as many words as men and took more turns on average than men. These findings contradict those showing that men tend to speak more and more often based on a sociolinguistic study of workplace conversations between male and female colleagues (Woods, 1989). However this could partly be accounted for by the setting of the research interview in the present study and the nature of the long-standing, intimate relationship between participants who were likely to be more comfortable and familiar in their interaction as husband and wife in comparison to work colleagues. The present study indicates that previous findings based on joint interviews (mainly with couples and informal carers and care recipients from a range of ages) on various health related topics showing that women speak significantly more than men and more often than men (Seale, Charteris-Black et al. 2008) extend to couples of advanced older

age focusing on the experience of stroke. It is important to acknowledge that the topics of health and illness are traditionally regarded as topics where women's experiences predominate (Seale, Charteris-Black et al. 2008) and as participants in the present study were of advanced older age it could be argued that this traditional gender divide is partly reflected in the joint narratives, regardless of whether or not the stroke survivor was male or female. This indicates the possible influence of older age on the different ways in which men and women participate in the construction of joint illness narratives.

However three joint narratives appeared to stand out from the overall pattern of interaction because the husbands took a dominate role, speaking significantly more than their wives. These men spoke just over half of the total words spoken during the interview (see table 9, page 231). David (spouse) took the lead in his joint interview, speaking over half (53.78%) of the total words compared to his wife Molly (stroke survivor) who spoke a third of the words (33.54%). David 'held the floor' during the interview, frequently making jokes and telling anecdotes where Molly was more softly spoken and tended to speak when her husband invited her collaboration with the use of questions tagged on to his speech, such as 'Isn't it?' or 'Don't you think?'. It appeared that this was perhaps likely to reflect the established pattern of their interaction within their long-standing marital relationship, more generally. John (spouse) also spoke more (51.88%) than his wife Helen (stroke survivor) (31.22%). At times he seemed to be speaking on her behalf, appearing to be protective of her. This was perhaps partly due to her frailty as Helen used a wheelchair following the amputation of one of her lower legs as a result of diabetes. Despite also being in bad health due to heart problems and also using a wheelchair due to leg ulcers and osteoarthritis John took more of a

lead role in the narrative and both John and Helen presented him as a capable carer and husband, talking about the different tasks he fulfilled. Tom, a stroke survivor, (51.01%) also spoke more than his wife Nora (38.22%) as he was talking more about his personal experience of the stroke. However it is important to note that although these three men spoke more than their wives they still spoke less than the mean average percentage of total words spoken by women in joint interviews (61.31%).

Table 9. Percentage of words spoken in joint interviews by gender

<i>Joint interview ID number</i>	<i>Participants (n= 26) (stroke survivor in bold)</i>	<i>Percentage of words spoken by men (n=13)</i>	<i>Percentage of words spoken by women (n=13)</i>
16	Ted Rita	24.12	70.77
22	Richard Judy	5.79	84.98
17	Sarah Nelson	8.89	67.98
11	Patrick Betty	38.89	44.58
29	Gretal Vas	8.61	67.98
15	Molly David	52.78	33.54
13	Jack Penny	35.23	59.83
24	Grace Simon	18.35	64
32	Eric Irene	10.89	78.18
23	Hilary Adam	11.20	77
18	Helen John	51.88	31.22
19	Tony Cathy	29.12	63.35
30	Tom Nora	51.01	38.22
Mean	-	26.75	61.31
Median	-	24.15	64

In summary, individual interviews lasted longer than joint interviews. This may be partly explained by the lower levels of social contact of both male and female stroke survivors participating in individual interview, linked with their predominant marital status as widows/ widowers, and so they took the opportunity to present their experiences during the interview. This indicates the influence of older age, widowhood, loneliness and social support networks on the construction of illness narratives.

In individual interviews men took more turns than women and spoke more words but in joint interviews women were more likely to dominate, speaking more words and taking more turns. It is possible that wives' conversational dominance may partly reflect the established patterns of interaction within the long-standing marital relationships more generally (this is discussed further in relation to narrative type on page 239), with the exception of three couples where husbands took the dominant role in the narrative. This indicates that the marital relationship as well as the interview context (ie individual or joint) is likely to influence the ways in which older men and women engage in self-presentation in illness narratives.

The next section discusses women's and men's talk about personal and shared experiences in joint interviews.

Gender and talk about personal and shared experiences in joint interviews

Overall, in joint interviews women's experiences were more prominent than men's as they spoke more about both their personal and shared experiences, unlike the individual interviews where men spoke more about their personal and shared experiences.

In the joint interviews women spoke more than twice as many singular pronouns and more than twice as many plural pronouns than men indicating that they talked much more about their personal and shared experiences than men (see table 10, below). This reflects the dominate role of women in the joint interviews more generally, with wives speaking more than twice as many words as their husbands on average.

Table 10. Mean number of singular and plural pronouns used in joint interviews by gender

	Men (n= 13)	Women (n= 13)
Mean no. of singular pronouns	123	308
Median no. of singular pronouns	112	268
Range of number of singular pronouns	12-489	24-900
Mean no. of plural pronouns	23	54
Median no. of plural pronouns	18	60
Range of number of plural pronouns	0-71	8-108

The current findings extend those from previous studies that women talk more about shared experiences than men based on joint interviews with participants of various ages talking about a range of health and illness topics (Seale et al. 2008), indicating that for older stroke survivors and their spouses, women spoke more about both personal and shared experiences.

Table 11. Singular and plural pronouns spoken as a percentage of the total number of pronouns spoken in joint interviews

<i>Narrative type</i>	<i>Joint interview ID number</i>	<i>Participants (n= 26) (stroke survivor in bold)</i>	<i>Singular pronouns spoken as a % of all pronouns (plural %)</i>
Conflictual (n= 3)	16	Ted Rita	91 (9) 89 (11)
	22	Richard Judy	86 (14) 83 (17)
	17	Sarah Nelson	96 (4) 89 (11)
Collaborative (n=4)	11	Patrick Betty	88 (12) 82 (18)
	29	Gretal Vas	88 (12) 80 (20)
	15	Molly David	71 (29) 75 (25)
	13	Jack Penny	94 (6) 75 (25)
Collaborative on a continuum (n= 6)	24	Grace Simon	92 (8) 72 (28)
	32	Eric Irene	98 (2) 91 (9)
	23	Hilary Adam	91 (9) 100 (0)
	18	Helen John	86 (14) 58 (42)
	19	Tony Cathy	74 (26) 60 (40)
	30	Tom Nora	77 (23) 69 (31)

Table 11 (see page 234) shows the proportion of singular pronoun use (I, me, my, mine, he, she) and plural pronouns use (our, we, we've, we're us) in joint interviews as a percentage of the total number of pronouns spoken, in relation to narrative type (based on the coding scheme developed by Veroff et al, (1993)). This indicates whether each participant spoke more about their personal experiences or shared experiences. Although overall women spoke more about personal and shared experiences compared to men, as a proportion of each participants' narrative, men spent more of their narrative talking about their personal experiences and women spent more of their narrative talking about their shared experiences. This implies that men were more likely to engage in presentation of the self during their narratives, based on their own views and experiences, whereas women were more likely to engage in co-presentation, constructing views and experiences, including the stroke, as a shared experience, supporting the presentation of a couple identity. This is illustrated by the example below, showing a wife presenting her husband's stroke as a shared experience (using 'we', 'we've' and 'us').

*It's only since he had his stroke that **we** realised that **we** just can't live here (in this block of flats) anymore. It's too high up and **we** can't rely on the lifts. I mean **we've** had to walk the stairs many a time before he had the stroke, and it crucified **us** walking up the – all those flights. So, you know, and no way **we** could do it now. So **we'd** been stuck in.*

(Judy, aged 68, married)

However an exception to this pattern were four couples where the wife, who was the stroke survivor, spent more of her narrative talking about personal experiences than her husband did (Sarah/ Nelson, Greta/ Vas, Grace/Simon, Helen/John). This indicates that differences in the amount that participants

talked about personal or shared experiences during the narrative may also be related to status as stroke survivor/ spouse as well as gender. It was expected that stroke survivors would be more likely to use a higher proportion of words talking about personal experiences as the participants were asked to 'tell the story of your stroke' during the biographical narrative interview. This is discussed further in the next section examining differences between the participation of stroke survivors and spouses in joint interviews.

Stroke survivors and spouses participation in joint interviews

Overall, stroke survivors and spouses participated in a balanced way in terms of number of words spoken and turns taken, with spouses speaking slightly more words.

In the joint interviews stroke survivors and spouses spoke similar numbers of words with spouses speaking slightly more words and stroke survivors taking slightly more turns than spouses (see table 12, page 238). Although it might have been expected that stroke survivors would participate more than their spouses in the joint interviews because the topic of the biographical narrative interview was the story of their stroke, this was not the case. One possible explanation for spouses speaking slightly more could be due to the poorer health of the stroke survivors, as identified in a joint interview study of people with cancer and their informal carers (mainly spouses) where participants spoke a similar number of words, except where the person with cancer was in poor health (Morris, 2001).

It is also important to note that those stroke survivors with aphasia may have participated less in the narrative compared to their spouses. Of the joint interviews there were three stroke survivors who had aphasia (as discussed previously). Tony, who spoke slowly and with a slight stutter, getting words mixed up occasionally, spoke 29% of the total words spoken during his interview whereas his wife Cathy participated over twice as much, speaking 63% of the total words (see table 9, page 195). However Sarah who spoke slowly and slurred her words, spoke 69% of the total words compared to her husband Nelson who only spoke 9% and Tom who had slightly slurred speech spoke 51% of words compared to his wife who spoke 38%. Therefore, for these two stroke survivors, having aphasia did not mean that they participated in the joint interviews less than their spouses.

Table 12. Mean number of turns and words for stroke survivors and spouses in joint interviews

	Stroke survivor (n= 13)	Spouse (n= 13)
Mean no. of turns	147	130
Median no. of turns	111	74
Range of turns	35-341	32-316
Mean no. of words	2484	3890
Median no. of words	2642	3344
Range of no. of words	571-4886	384-9753

However although spouses spoke slightly more words than stroke survivors, stroke survivors used a higher percentage of singular pronouns in their narratives (see table 11, page 234). This indicates that although they were speaking slightly less than their spouses, when they talked it was more about their personal experiences than shared experiences, which is to be expected as the main focus of the interview was initially their experience of stroke. Two couples (Molly/ David, Hilary/ Adam) were the only exception to this pattern as the husbands talked slightly more about their personal experiences compared to their wives who were stroke survivors. For David and Molly this reflected his general dominance in the narrative (David spoke 53% of total words compared to Molly who spoke 34%). Adam only used pronouns in his narrative when speaking about personal experiences and did not talk about shared experiences as he did not use any plural pronouns. This largely

reflected his wife's conversational dominance (Adam spoke 11% of total words compared to Hilary who spoke 77%). Unlike David, he allowed Hilary to do the majority of talking and would generally participate only when his wife invited him to with a question or comment addressed to him.

In summary, stroke survivors and spouses generally participated in the narrative in a similar way in terms of number of words spoken and turns taken, with spouses speaking slightly more words which may be due to the poorer health of the stroke survivors. However stroke survivors were more likely to talk about their personal experiences compared to spouses, and therefore spent more of their narrative engaging in the presentation of self, which is likely to be because stroke was the main focus of the interview. The findings suggest that the health of participants and the informal caring role of spouses influence participation in the co-construction of joint illness narratives.

The next section discusses gender differences in the joint interviews in relation to narrative type based on Veroff et al's (1993) coding scheme, providing a further layer to the comparative keyword analysis, building on previous findings presented in Chapter Five.

Gender and narrative type in joint interviews

Overall, the comparative keyword analysis supported couples' narratives types, identified as mainly conflictual, mainly collaborative and collaborative on a continuum, based on Veroff et al.'s (1993) coding scheme (see Chapter Three, page 81).

Couples engaging in collaborative narratives, displayed a more balanced pattern of interaction compared to other narrative types. Men and women displaying collaborative narratives took more turns than other narrative types, and took roughly equal numbers of turns, tending to follow a pattern of a conversation going back and forth, with neither participant dominating the interview. In collaborative interviews narratives about personal experiences were fairly equally shared amongst men and women, however men talked much more about personal experiences than in other narrative types of interviews. Conflictual narrative interviews were characterised by wives' interactional dominance, with women speaking much more than men and speaking more about their own personal experiences regardless of whether or not they were a stroke survivor or a spouse. In conflictual interviews men spoke less about their personal experiences and very little about shared experiences. The wives of the three couples engaging in mainly conflictual interviews were frustrated about particular experiences surrounding the stroke (as discussed in Chapter Five) and took the opportunity during the interview to talk about these issues from their own perspectives. In joint interviews where narratives were collaborative on a continuum both men and women spoke fewer words than those in collaborative and conflictual interviews. Men and women took a similar number of turns but women spoke nearly three times as many words, speaking more about their personal and shared experiences than men. However women in these interviews spoke less than women in collaborative and conflictual interviews.

Across all three types of narratives, on average, women spoke more words than men. However the greatest gender difference was in narratives that were mainly conflictual with women speaking more than five times the

number of words than men based on the mean average and more than 14 times based on the median (see table 13, below).

Table 13. Mean number of turns and words in joint interviews by gender and narrative type

	<i>Narrative type</i>					
	Mainly conflictual (n=3)		Mainly collaborative (n= 4)		Collaborative on a continuum (n= 6)	
	Men (n=3)	Women (n=3)	Men (n= 4)	Women (n= 4)	Men (n= 6)	Women (n= 6)
Mean no. of turns	83	96	196	228	94	114
Median no. of turns	64	121	105	121	70	79
Range of no. of turns	64-111	36-132	54-341	54-354	32-186	35-289
Mean no. of words	1331	6872	3310	4838	1091	3186
Median no. of words	571	8378	3987	4571	1448	2001
Range of no. of words	466- 2955	3568- 8669	505-4764	2971-7240	384-1809	640-9753

In the joint interviews the number of turns that men and women took tended to be quite similar across the narrative types based on the mean (see table 13, above). However based on the median women in conflictual narratives took approximately twice as many turns. When comparing across narratives types, couples engaging in collaborative narratives took approximately twice as many turns based on the mean than those in mainly conflictual interviews

and interviews that were collaborative on a continuum. At times the wives in interviews that were collaborative appeared to invite and encourage their husbands to participate, as seen in the following example with Penny using questions tagged on to the end of her sentences to invite her husband to take a turn:

Jack: I mean I gradually progressed to what I am now. I can stand with that, I can get to the stairs with that (walking frame). I can walk up and down the stairs on me own, can't I?

*Penny: Yes. It's his balance as well. **Your balance isn't it?***

J: Oh my balance, yes, I've got no balance....There are certain things I can do. I mean.

*P: You can't lift anything up, **can you?***

J: No. I'm alright with that hand. I can hold, pull myself up, get meself up the stairs with that.

(Jack aged 79 and Penny aged 59)

Overall, the comparative keyword analysis supported couples' narratives types, validating previous findings presented in Chapter Five, based on Veroff et al's (1993) coding scheme.

The next section examines talk about personal and shared experiences in joint interviews in relation to gender and narrative type.

Gender, narrative type and talk about personal and shared experiences in joint interviews

Overall, Men and women in collaborative interviews talked more about shared experiences than other narrative types and talked about personal experiences more equally. In conflictual interviews women talked much more about both personal and shared experiences than men, reflecting their general conversational dominance.

In joint interviews that were collaborative in style, men and women engaged equally in talk about personal experiences, compared to other narrative types (see table 14, page 244).

The following quote is an example of talk about personal experiences (use of 'I', 'me', 'my') from a husband (stroke survivor) in a collaborative joint interview:

*I went out on the Friday, then went out on the Saturday evening, but when I wanted to get up on Sunday morning, I just collapsed. I couldn't get up. She (my wife) called **my** daughter and they put me back on the bed and they called the ambulance. When they get me in to (hospital), they realised **I'd** had a stroke. So they gave me x-rays and all the rest of it. I was in (hospital) for five or six weeks... But then once I got home, I couldn't do a thing. I would get into bed, my wife had to get me out and got **me** a chair.*

(Jack, aged 75, married)

Table 14. Mean number of singular and plural pronouns used in joint interviews by gender and narrative type

	<i>Narrative type</i>					
	Mainly conflictual (n= 3)		Mainly collaborative (n= 4)		Collaborative on a continuum (n= 6)	
	Men (n= 3)	Women (n= 3)	Men (n= 4)	Women (n= 4)	Men (n= 6)	Women (n= 6)
Mean no. of singular pronouns	77	458	239	282	69	250
Median no. of singular pronouns	44	513	222	269	75	133
Range of no. of singular pronouns	16-172	347-513	24-489	164-425	12-120	48-900
Mean no. of plural pronouns	9	62	34	69	21	40
Median no. of plural pronouns	7	66	30	64	25	29
Range of no. of plural pronouns	2-18	13-108	6-71	59-89	0-43	8-85

The mean number of singular pronouns used by men and women in interviews that were mainly collaborative in style was fairly similar, indicating that narratives about personal experiences were balanced amongst men and women.

Women from couples engaging in 'collaborative on a continuum' narratives talked more about personal and shared experiences than men but the difference was less pronounced than for couples engaging in conflictual narratives.

Women used a far greater number of singular pronouns than men in the three joint interviews where the narrative style was mainly conflictual (see table 14, above). Based on the mean average, women used almost six times more singular pronouns than men in conflictual interviews indicating that women talked much more about their personal experiences than men. The three women in these interviews were frustrated about particular experiences surrounding the stroke (as discussed in Chapter 5, page 202) and took the opportunity during the interview to talk about these issues, dominating the narratives. In one of these couples the stroke survivor was a women, Sarah, and she talked at some length about her experience of the stroke and coping without her husband who had been admitted to a mental health unit shortly after her stroke. In the other two interviews Judy and Rita were wives of stroke survivors and they talked at length about their own experiences of caring for their husbands, who were both partially sighted, and the challenges they had experienced, particularly in the context of their own health problems. This is illustrated by the quote below from a wife engaging in a mainly conflictual narrative talking about personal experiences (use of 'I', 'me', 'my'):

*I can't manage him, obviously I couldn't manage him, but um 'cause I've had a heart attack myself... Well I've had three stents put in as well you see so, obviously I can't, when he falls I can't pick him up. And I've also got arthritis all over **my** back and I just can't whats-a-name, so I can't cope with him. If he falls he falls. He has to lay there till someone comes to pick him up or he picks himself up. 'Cause he's a dead weight, when you fall you're a dead*

*weight, so it's impossible for **me** to bend down and pick him up. I should say his life, his whole life has changed.*

(Rita, aged 83, married)

Women in conflictual couples used over six times more plural pronouns based on the mean average than men who used very few plural pronouns, indicating hardly any talk about shared experiences (see table 15, page 248). Men and women in collaborative interviews spoke the most about shared experiences compared to other narrative types.

In summary, men and women in collaborative interviews engaged more in co-presentation of shared experiences than other narrative types and engaged much more equally in their self-presentations of personal experiences. In contrast, in conflictual interviews women engaged much more than men in co-presentation of shared experiences and self-presentation of personal experiences, reflecting their general conversational dominance. This provides strong support for couples' narratives types, based on Veroff et al's (1993) coding scheme.

Gender, narrative type and use of 'he and 'she'

Overall, women generally used 'he' and 'she' more than men but differences were identified across narrative types with women from conflictual couples more likely to talk about their husbands during the interview and men from collaborative couples more likely to talk about their wives.

All men used far less 'he' pronouns and women used far more, which is to be expected as women used 'he' to refer to their husbands during the interview (see table 15, page 248). However it is important to acknowledge that the use of 'he' and 'she' during the narratives also refers to other people including relatives, friends, neighbours and health care professionals.

Women used many more 'he' words than men generally but the largest difference was amongst couples engaging in conflictual narratives indicating that they spent more time talking about their husbands. Men engaging in conflictual narratives spoke more 'she' words than men from other narrative types, based on the mean, indicating that they were more likely to talk about their wives.

Table 15. Mean number of ‘he’ and ‘she’ words used in couple interviews by gender and narrative type

	<i>Narrative type</i>					
	Mainly conflictual (n= 3)		Mainly collaborative (n= 4)		Collaborative on a continuum (n= 6)	
	Men (n =3)	Women (n= 3)	Men (n= 4)	Women (n= 4)	Men (n= 6)	Women (n= 6)
Mean no. ‘he’ words spoken	10	134	20	115	9	60
Median no. of ‘he’ words spoken	2	140	17.5	38.5	5.5	40
Range of number of ‘he’ words	0-27	45-216	0-43	20-363	0-24	2-162
Mean no. of ‘she’ words spoken	10	75	35	33	9	34
Median no. of ‘she’ words spoken	11	24	34	65.5	15.5	4
Range of no. of ‘she’ words	6-13	15-186	11-62	14-45	1-29	3-169

Drawing on the approach of Seale, Ziebland et al.’s (2006), the context of the use of ‘he’ and ‘she’ was analysed in a subsample of three couple interviews from each of the narrative types. These were Greta/ Vas (mainly collaborative), Tom/ Nora (collaborative on a continuum) and Richard/ Judy (mainly conflictual). Participants’ use of ‘he’ and ‘she’ was categorised as positive, negative or neutral according to the context in which it was used.

The following is an example of a positive use of 'he';

*I'm positive. I don't say oh poor me, I'm not, always millions of people worse off than I am. That helps. I have a very very supportive husband. Sometimes **he** means too well with me (laughs).*

(Gretal, aged 78, married)

Below is an example of a neutral use of 'she';

*Someone rings up and I say hello, yes and I have to call her (wife). I'm a bit deaf as well. I'm a little bit deaf. So um I say who's that so and so and **she** says you know who it is, eventually it comes.*

(Tom, aged 80)

The following is an example of a negative use of 'he';

Richard: *Someone down the pub said, 'I've just been up to your house, your wife has lost her voice.' So I had to leave to come home and enjoy it!*

Judy: ***He's** being sarcastic now. There's nothing wrong with his brain, that's for sure!*

(Richard, aged 83 and Judy, aged 68)

Although in the above example Richard is joking about his wife talking a lot, the tone and manner in which the couple were speaking to each other indicated a negative context for Judy's use of 'he'.

Findings showed that all of the 'he' and 'she' words used by Tom and Nora (collaborative on a continuum) were neutral. All of the 'he' and 'she' words used by Gretal and Vas (collaborative) were neutral with the exception of four positive 'he's' used by Gretal (one to refer to her son and three to refer to her husband). The majority of the 'he' and 'she' words used by Richard and Judy (conflictual) were neutral with the exception of eight negative 'he's' used by Judy (five to refer to her husband and three to their GP who made a home visit when Richard had a stroke). Therefore in the subsample the collaborative couple were the only one to use 'he' and 'she' positively and the conflictual couple the only couple to use 'he' and 'she' negatively and the collaborative on a continuum couple used 'he' and 'she' only in a neutral way. Therefore, importantly these findings support the narrative types providing a method of triangulation. In this subsample, men's use of 'he' and 'she' was always neutral and it was only women who used these pronouns in a positive or negative way. This indicates that they talked more about feelings and emotions in relation to people, as identified in a study showing that women use a greater number of 'people' words (eg. 'he', 'she', 'husband') and demonstrate more emotional expressivity than men during individual interviews on the experience of cancer (Seale, Ziebland et al. 2006). This indicates that traditional gender differences in the use of language apply to men and women in advanced older age.

Gender and use of spouse's names

Overall, women were far more likely to refer to their spouse by name, but this was not related to narrative type.

All of the joint interviews were analysed for the number of times participants referred to each other by name. Ten of the 13 wives referred to their husbands by their name at least once (see table 16, page 253). Judy (42 times) and Greta (25 times) used their husband's name the greatest number of times, far more than any other wife. However only three husbands referred to their wives by their name and this was very infrequent with John using his wife's name seven times and Patrick and Simon only using their wife's name once. The frequency of referring to a spouse by name clearly differed according to gender but did not appear to relate to narrative type. Instead of referring to their wives by name men tended to use 'her' and 'she' or 'my wife' or 'the wife', as can be seen in the quote below.

*I've gradually improved, I didn't – the physiotherapy come round and he sort of got me up sort of with the frame, just scrambling along with the frame, and up and down stairs - I would get upstairs if, which I couldn't before. So I can do that on me own now. Before **the wife** had to do all that. So I've got that... So then the only thing I couldn't manage was sort of washing my back, obviously, which **the wife** does.*

(Jack, aged 79)

It is important to note that using names to refer to a spouse or terms such as 'the wife' would influence the number of singular pronouns spoken.

Women were far more likely to refer to their spouse by name, supporting previous findings that women use more 'people' words (eg. 'he', 'she', 'husband') than men in individual interviews on the experience of cancer with participants from a range of ages (Seale, Ziebland et al. 2006). This also provides support to findings that women use personal names considerably

more than men do based on analysis of the spoken English component of the British National Corpus (BNC) from 1991-1995 (Rayson, Leech et al. 1997). The spoken component of the BNC consists of transcriptions of 10 million words of unscripted informal conversations recorded from a representative sample of volunteers from different age groups, regions and social classes and spoken language collected in different contexts, eg. Formal business meetings, government meetings, radio shows and phone-ins. The present findings on use of spouse's names provide further indication that traditional gender differences in the use of language apply to men and women in advanced older age.

Table 16. Number of times joint interview participants referred to their spouse by name

<i>Narrative type</i>	<i>Joint interviews ID number</i>	<i>Participants (n= 26) (stroke survivor in bold)</i>	<i>No. of times participant referred to their spouse by name</i>
Conflictual (n= 3)	16	Ted Rita	0 4
	22	Richard Judy	0 42
	17	Sarah Nelson	0 0
Collaborative (n= 4)	11	Patrick Betty	1 1
	29	Gretal Vas	25 0
	15	Molly David	4 0
	13	Jack Penny	0 0
Collaborative on a continuum (n= 6)	24	Grace Simon	9 1
	32	Eric Irene	0 0
	23	Hilary Adam	2 0
	18	Helen John	5 7
	19	Tony Cathy	0 4
	30	Tom Nora	0 4
	Total	Females Males	118 18
	Mean	Females Males	9.08 1.38
	Range	Females Males	0-42 0-7

In summary, the joint interview data indicates clear differences in the way in which people engage in the construction of illness narratives according to gender and narrative type. Overall women spoke nearly three times as many words as men, speaking more about their personal and shared experiences. Across the narrative types, men and women in collaborative narrative couples engaged in a more balanced style of narrative, taking twice as many turns as other narrative types. Men and women in collaborative interviews engaged more in co-presentation of shared experiences than other narrative types and engaged much more equally in their self-presentations of personal experiences. Men in collaborative interviews presented more about personal experiences than men in other narrative types. In contrast conflictual narrative interviews were characterised by women's conversational dominance, engaging much more in self-presentation of personal experiences. In conflictual interviews men engaged in less self-presentation of personal experiences and very little of shared experiences. In interviews where narratives were collaborative on a continuum both men and women spoke fewer words than those in collaborative and conflictual interviews and took a similar number of turns but women spoke more words, presenting more about on their personal and shared experiences than men.

Discussion

One key finding is that men participated more than women in the construction of narratives during individual interviews, in answer to the sub research question 'in individual and joint interviews does the amount participants speak and how often differ according to gender?'. This contradicts findings from previous studies that women spoke more words and took more turns in individual interviews (Seale, Charteris-Black et al. 2008; Seale and Charteris-Black 2008). One possible explanation could be that in the present study the men in individual interviews were lonelier and did not have as much opportunity to talk with friends and family as the women, who are more likely to have wider social and support networks in old age (Arber and Ginn 2005).

In joint interviews women participated more in the construction of narratives, indicating that previous findings based on participants from a range of ages (Seale, Charteris-Black et al. 2008) extend to older age groups. Topics of health and illness are traditionally regarded as topics where women's experiences predominate (Seale et al. 2008) and as participants in the present study were of advanced older age it could be argued that this traditional gender divide is partly reflected in the joint narratives, regardless of whether or not the stroke survivor was male or female. Clear gender differences in language use were also identified with women using their husbands names more and using many more 'he' and 'she' pronouns, and using them in a 'positive' or 'negative' context. This reflects findings from participants from a range of ages that women are more likely to use 'people' words and engage in emotional expressivity (Boneva and Kraut 2002; Seale, Ziebland et al. 2006). In the present study some men were identified as adopting an external perspective on illness experience by speaking in a

generalised way and avoiding the use of first person pronouns, demonstrating less emotional expressivity. This was a strategy used by men from a range of ages participating in interviews on the experience of a wide range of illnesses (Charteris-Black and Seale, 2009). The present findings indicate that traditional gender differences in language use apply to older age groups and therefore gender has an important influence on the way in which older people engage in the construction of narratives to make sense of the experience of illness.

In answer to the sub research question ‘in individual and joint interviews does talk about personal experiences and shared experiences differ according to gender?’ women’s experiences were more prominent than men’s in joint interviews as they spoke more about both their personal and shared experiences, unlike the individual interviews where men spoke more about their personal and shared experiences. It is important to acknowledge that in individual interviews widows also talked about their spouses and previous shared experiences, as well as in joint interviews. The death of a spouse was a very prominent theme in some participants’ presentation of self, often more so than the stroke, even when it had occurred a number of years ago (as discussed in Chapter Five). Individual interviews lasted longer than joint interviews which may be partly explained by the lower levels of social contact of both male and female individual stroke survivors generally, linked with their predominant marital status as widows/ widowers, with widowhood consistently linked to the experiences of loneliness and social isolation (Victor et al. 2000). Therefore stroke survivors in individual interviews may have taken the opportunity to talk more, constructing longer narratives. This indicates the influence of widowhood, loneliness and social isolation, all

associated with older age, on the construction of illness narratives and presentation of self.

In relation to the sub research question ‘in the joint interviews is there a difference in the way in which stroke survivors and spouses participate in the narrative?’ there were no major differences identified in the amount stroke survivors and spouses participated in the narratives, even taking into account that three of the stroke survivors had aphasia. Stroke survivors engaged in a higher proportion of self-presentation than their spouses based on talk about personal experiences, indicating that they were almost equally as active in the construction of joint narratives. However spouses spoke slightly more words overall possibly due to the poorer health of the stroke survivors, as identified in a joint interview study of people with cancer and their informal carers (mainly spouses) where participants spoke a similar number of words, except where the patient was in poor health (Morris 2001). This indicates that poor health and informal caring roles are likely to influence the construction of illness narratives and presentation of self.

In addressing the sub research question ‘in the joint interviews, are there gender differences in participation in the narrative according to narrative type (drawing on Veroff et al.’s (1993) coding)?’ the findings indicate clear differences in joint interviews according to gender and narrative type, based on the systematic and rigorous method of comparative keyword analysis. This provides a method of triangulation, further validating the narrative types based on

Veroff et al.'s (1993) coding scheme (as discussed in Chapter Five). Gender differences in the structure of collaborative narratives were less pronounced, with a more equal amount of turn taking between men and women, reflecting a conversational style, and men and women both engaged equally in the presentation of the self, indicated by singular pronoun use. On the other hand conflictual narratives were characterised by wives taking a more dominant role speaking much more and engaging more in the presentation of self. The findings that women participated more in joint interviews, particularly in the mainly conflictual narratives, differs from findings of previous sociolinguistic studies that men tend to speak more and more often in mixed sex settings (Woods 1989) and display more 'non-cooperative' language patterns (Coates 2004). The dominance shown by women in the mainly conflictual narratives may have reflected the general nature of these couples' marital relationships in which the wives took a dominant role in conversational interaction with their husbands. However their relationships may have changed over time and for two of the couples, relationships are likely to have been shaped by the men's ill health and high level of physical dependency, with the nature of the marital relationship known to be influenced by illness and disability (Walker and Luszcz 2009). It is also important to note that had the two individual participants who were married been interviewed with their wives, they may have indicated some conflictual interaction as both men briefly discussed some conflict with their wives as a result of the stroke.

There are limitations in findings based on a relatively small sample of 14 individual interviews and 13 joint interviews (40 participants in total), the size of which was partly constrained by time and resources. As noted in the methods (page 88), statistical analysis was conducted to investigate the relationship between number of words spoken, number of turns taken, number of plural pronouns used and number of singular pronouns used in relation to gender, status as a stroke survivor or spouse and type of narrative (ie. mainly collaborative, mainly conflictual, or collaborative on a continuum). However results indicated no significant relationships due to a small dataset therefore the findings focused on the patterns indicated by the comparative keyword analysis. However it is of note that Seale, Charteris-Black et al (2008) based their comparisons on 58 individual interviews and 37 joint interviews (132 participants in total) which is also a relatively small sample and only approximately two thirds greater than the sample size of the present study. The comparative keyword analysis was used as an exploratory method in the present study and was also used in combination with a coding framework of narrative types (Veroff et al, 1993), which provided a further means of exploratory analysis and validation of the couples' narrative types, as discussed above.

In conclusion, to address the overall research question 'in what ways do older couples engage in the co-construction of narratives to make sense of the stroke?', the comparative keyword analysis suggests that how people make sense of the experience of illness through the construction of narratives and the presentation of identity is not only influenced by gender, but also interview context (ie individual or joint) and narrative type, within the context of the marital relationship, widowhood, older age and ill health.

The next chapter presents the methodological contributions of this thesis and discusses the findings as a whole, before presenting implications for policy and practice and suggesting recommendations for further research.

Chapter 7: Discussion and conclusions

Introduction

Stroke is one of the leading causes of adult disability in England, with half of all stroke survivors living with a significant impairment and relying on others for care (Stroke Association, 2016). More people are living with stroke in old age as the risk of stroke increases with age and higher numbers of stroke patients are surviving, although many experience significant disability. Although stroke has been the subject of many epidemiological studies it is also significant for sociological studies examining the impact of chronic illness on the identity of older people. Stroke causes a greater range of disability than any other condition (Adamson et al., 2004) and unlike other chronic conditions, the impact of stroke is sudden often leaving the individual and their family initially unprepared to deal with the consequences. Many older stroke survivors are living with multiple chronic conditions, but so too are their informal carers, who are often spouses.

Studies on biography and narrative (re)construction in relation to the experience of stroke have mainly focused on participants from a range of ages (Kaufman, 1998., Pound et al., 1998, Faircloth et al., 2004, France et al., 2013) but none have focused specifically on those in advanced older age. Empirical studies on identity in older age more generally are also lacking. This thesis has begun to address these gaps by focusing on the impact of stroke on identity amongst stroke survivors (aged 75 and over) and their spouses. This thesis has drawn on two different theoretical approaches to identity. First, Giddens' (1991) notion of identity as a set of reflexive biographical narratives that continually integrate life events in the external

world, informed the theoretical framework. For Giddens (1991), biographical narratives refer to the story of who we are and how we came to be where we are now. His structuration theory integrates both macro-level structural theories and micro-level agency approaches, emphasising the relationship between the two. He argues that structures are created, maintained and changed through actions, while actions are given meaningful form through the background of social structure. His concept of fateful moments refers to a transition point in life, such as the experience of a stroke, that has major implications for self-identity and ontological security. Ontological security refers to a 'protective cocoon' and a sense of 'invulnerability' which blocks off negative possibilities about the risks implied during everyday life which could threaten bodily or psychological integrity, in favour of a generalised attitude of hope deriving from basic trust. The concept of fateful moments built on Giddens (1979) earlier notion of 'critical situations' that informed Bury's (1982) seminal work conceptualising chronic illness as biographical disruption. This theoretical approach informed the thematic analysis carried out for Chapter Five examining personal identity and how stroke was experienced as a biographical disruption and the ways in which participants responded. The second theoretical approach to identity that informed the framework of this thesis was Goffman's (1959) micro-level approach, focusing on how personal identity is constructed during social interaction in everyday life through the presentation of self, or managed performances. He emphasised the significance of language and interaction in the construction of the self. Therefore the analytic approach was based on the assertion that participants were engaging in a social performance during the interviews and the narrative data were analysed as shared meanings constructed through social interaction. This symbolic interactionist approach informed both the analysis presented in Chapter Five focusing on the interaction between

spouses and the analysis presented in Chapter Six drawing on a sociolinguistic perspective.

In line with these theoretical approaches, unstructured biographical narrative interviews were carried out with stroke survivors aged 75 and over and joint interviews with their spouses. The interviews, drawing on Rosenthal's (2004) biographical-narrative method, began with an open question asking the participants to tell the story of their stroke. The aim was to elicit a detailed narrative indicating how participants made sense of the stroke, what meanings they attached to it, how they presented themselves and how they attempted to locate the stroke in their overall biography. As stated, the data were analysed using three methods to examine three different aspects of older people's experiences of living with stroke. Chapter Four presented findings based on a thematic analysis, discussing salient aspects of participants' identity, demonstrating the significance of aspects of personal identity other than stroke. Findings presented in Chapter Five based on the analysis of the joint interviews enabled an understanding of couple's co-presentations and different styles of social interaction. The novel approach to analysis was based on a method of coding interaction between couples (Veroff et al. 1993), coding each shift in speaker which indicated couples' narrative styles as either predominately conflictual or collaborative. Chapter Six examined differences in the sociolinguistic construction of narratives in relation to gender, interview context (individual or joint), narrative style and differences between stroke survivors and spouses. The systematic comparison of individual interviews and joint interviews was carried out based on a novel approach to analysis, which involved comparative keyword analysis techniques (Seale, Ziebland et al. 2006), carried out in relation to the three styles of interaction developed in Chapter Five.

This chapter provides a summary and discussion of the methodological contributions and reflections and the main research findings. The chapter concludes by discussing implications of the study for policy and practice and suggests recommendations for further research.

Methodological contributions and reflections

Contributions

This thesis employed a novel approach, based on three forms of analysis of a single dataset of biographical narrative interviews with older stroke survivors and their spouses. First, thematic analysis examined narrative themes that were salient to participants' self-presentation, demonstrating the significance of an individual's biography for the meanings they assign to chronic illness. Second, analysis of joint interviews drew on Veroff et al.'s (1993) method of coding interaction between couples based on six codes applied to each shift in speaker, indicating couples' narrative styles as either predominately conflictual or collaborative. This enabled an understanding of couples' co-presentations but also how couples constructed these through different forms of social interaction. Third, a systematic comparison of individual interviews and joint interviews was carried out, building on the comparative keyword analysis techniques developed by Seale and colleagues (2006), and relating the findings to the types of couple co-presentations. This identified clear differences in the way husbands and wives engaged in the construction of narratives based on interview context (ie individual or joint interview) and the circumstances of the couples. With

the exception of work by Seale et al (2008), no other studies have been identified that have systematically compared individual and joint interview data based on a sociolinguistic approach.

The methods of analysis were systematic and practical to ensure required transparency, rigour and validity (Atkinson 1997). Analysis of joint interviews provided two layers of analysis based on comparative keyword analysis and a coding scheme to analyse interaction between couples, developing a systematic method specifically designed to analyse and compare data from individual and joint interviews. Importantly, the comparative keyword analysis carried out provides support for the narrative types identified based on the coding scheme for interaction between couples (Veroff et al. 1993), providing an original method of triangulation, further validating the methods. Demonstrating the value and practicality of the method of analysis for joint interviews developed in this thesis, a recent study by Riley (2014) drew on the interaction types used in the present study (Radcliffe, Lowton and Morgan, 2013) to analyse joint interviews with (non)retired farming fathers and sons in the UK, as discussed in Chapter Two.

This study has begun to address the gap in research using joint interviews within the context of illness experience. Much previous work based on joint interviews with couples would have benefited from moving beyond a purely thematic approach with minimal interpretation of the co-construction of narratives. A dyadic approach to analysis is important for understanding the effects of the disruptions of illness on the ill person but also on their significant other, as they are central to the experience, and the effects on the relationship between the couple. The analytic approach was based on the premise that couples were participating in a social performance (Goffman 1959) during the

interviews and the narrative data were therefore analysed as shared meanings constructed through social interaction. The access to interaction between the two participants with a pre-existing identity as a dyad provides a distinct analytic advantage for joint interviews. This approach to analysis of joint interview data has only been recognised recently in research in the field of health and illness (Polak and Green, 2015; Torge, 2013).

Reflections on the interview process

It is important to acknowledge the role of the researcher in the construction of the narratives in both joint and individual interviews, as Hyden states 'to listen to the narrative is to take an active part in its construction' (1997: 60). For example, the significant age difference between participants and the younger researcher may have influenced participants' presentations. As Rozario and Derienzis suggest, the much younger researcher may have 'served as an external reminder of their age, and their representations of themselves might be seen as reactions to this reminder' (2009: 551). The researcher's female gender may also have influenced the narrative, with the possibility that male participants may have felt less at ease talking about their stroke and other important issues in their life. However having the same interviewer carrying out all of the interviews was an advantage as this provided consistency in interview style and interviewer characteristics such as gender, age and ethnicity. The interviewer conducting the analysis also had the advantage of providing very useful context to the data, for example the tone and manner in which words were spoken and any inferred meanings.

Stroke survivors with severe memory problems, who lived in care homes and who were not able to communicate in English were excluded from the sample, therefore findings may have limited applicability for older stroke survivors from these groups. Those who had a stroke less than six months prior to the interview request were also excluded as it is likely that findings for these participants would differ due to time taken to adjust to possible biographical disruptions after an initial period of physical recovery after stroke. The sample were mainly from a working class background, based on previous occupation in manual employment, therefore findings are likely to be less

applicable to those from other social class backgrounds. However six participants were from middle class backgrounds, including two couples, based on previous managerial, administrative and professional occupations (Office of National Statistics, 2010). The majority of participants were White British and a third of participants were from Black and other ethnic groups. However this accurately reflects the ethnic make-up of the SLSR (Wang, et al., 2013).

As participants were already registered on the SLSR and most were therefore visited annually by a fieldworker to complete a questionnaire, they were somewhat familiar with discussing certain aspects of their stroke with professionals. Therefore some participants may have been used to participating in the social performance (Goffman, 1959) of the research interview, and perhaps presented similar narratives to those that had previously been told while answering SLSR questionnaires. Therefore for some, this may have meant they had more opportunity to construct a narrative to make sense of their stroke within the context of their biography. Those who had agreed to participate in an interview for the present study may differ from those who declined. For example, it may be possible that one of the reasons why the group of participants who talked about feeling lonely agreed to participate is because they were lonely. The small sample size may be also a potential methodological limitation, however a smaller sample enabled an in-depth analysis based on a novel approach. This has provided a detailed and valuable insight into how older people present themselves following a stroke and how older couples who have been married for many years interact with each other and participate in the co-construction of narratives to make sense of the experience of stroke.

A small number of participants presumed that I was a health care professional as the main topic of the interview was the experience of stroke. This meant that on occasions I was asked for advice regarding health issues or support available from social services. I made it clear that my role was as a researcher and I had no clinical training and would be unable to help them and directed them to their GP. Participants gave up their time to speak with me in an interview, often giving detailed accounts of very personal aspects of their life. I was aware that I was unable to offer them anything in return for sharing their narratives which sometimes made me feel uneasy. However the interviews did appear to be a cathartic experience for many participants, particularly the 'frustrated' carers and some of the stroke survivors who lived alone and appeared to be lonely and did not often get the opportunity to talk to people about their experiences and problems in detail.

Inviting stroke survivors to have their spouse (or another relative/ informal carer) present during the interview if they wished implicitly allowed the participant to choose whether or not to participate in a joint interview. However choosing to be interviewed alone may be difficult for some stroke survivors living with a spouse who they are dependent on for certain aspects of daily care. Apart from two male participants, all of those living with their spouse chose to be interviewed together and appeared to feel very comfortable in each others' presence. One of the married stroke survivors who was interviewed alone described an estranged relationship with his second wife of five years. He said that their relationship had been problematic before his stroke 18 months previously and he planned on seeing a lawyer shortly about a separation. Although she still lived with him he said she was hardly ever at home and did not help him at all. The other married stroke survivor who chose to be interviewed alone (although his wife was at

home in the kitchen while the interview took place in the living room) described some tension in their marriage since his stroke two years previously, due to her expectations of him to carry out certain chores, such as DIY. He described feeling guilty that he was no longer physically able to do these tasks as he had done prior to the stroke. This supports Polak and Green's (2015) argument that participants' choice about whether or not to be interviewed together provides data in itself as this may imply that couples choosing not to be interviewed together may be less likely to engage in a collaborative narrative in comparison to those who choose a joint interview. Certainly narratives of the two men who chose not to be interviewed with their wives, indicated a certain amount of conflict in their marriages, albeit of a different nature to each other. Although interaction was collaborative for some of the couples choosing to engage in joint interviews, other couples engaged in direct and indirect conflictual patterns of interaction, producing some of the richest data. It is also important to be aware that couples may underemphasise conflicts and spousal burden during a joint interview. It cannot be taken for granted that spouses are equal in the interview situation and researchers should be aware of any possible imbalances of power, as noted by Torge (2013). However I would argue that any imbalances of power are a very important aspect of the data, as demonstrated by the dominance of the wives in the 'frustrated' carer presentations. This dominance, underpinned by conflictual interaction, partly reflected the tensions linked to the wives' burden of care and their own ill health.

There is also the possibility that the interview questions may raise points of contention between the spouses that could lead to conflict. Based on the experience in this research it is advised that researchers 'debrief' participants after the interview and leave the interview on a positive note. Although

conflict did arise for some couples during these interviews it appeared to be over relatively long-standing issues that had previously been discussed amongst the couples. If any direct conflict were to escalate between couples that may cause emotional harm to participants it may be advisable to change the tone of the interview and focus on a different subject that would be less contentious for the couples.

Joint interview data were analysed as shared meanings constructed through social interaction, based on the premise that couples were participating in a social performance (Goffman, 1959). Joint interview data are constructed by both participants in a continual process of negotiation and can therefore be viewed as a 'particular form of "institutional talk"' (Seale and Charteris-Black 2008: 126). Therefore the interaction styles were identified in relation to couple interaction during a research interview or 'performance' rather than during a form of naturally occurring conversation. In the present study very little interaction between couples was coded as 'non-response', a code which indicates implicit conflictual interaction. This is likely to be because couples were participating in an interview rather than an everyday conversation in a natural setting. However drawing on Rosenthal's (2004) method of open questioning, beginning with the question 'Please tell me the story of your stroke', allowed participants as much freedom as possible to structure their own narratives.

In terms of the length and content of interviews it was evident that for the small group of participants who appeared to be 'surviving' due to poor health and the experience of discomfort and pain, interviews took less of a narrative form compared with the other stroke survivors, giving less detail and requiring more prompting. These narratives corresponded to Frank's (1995) 'chaos'

type of narrative, described as 'antinarratives' without temporal order, characterised by despair, hopelessness and vulnerability. Therefore researchers using narrative interview methods should take into account that the degree of ill health, pain and discomfort will inevitably have an impact on the nature and quality of the narrative constructed. Two of these participants were interviewed with their spouses (husbands) and to a certain extent the spouses bolstered their accounts. They also encouraged the stroke survivors to engage in a more positive self-presentation, presenting themselves as 'getting on' with life together as a couple, perhaps partly wanting to appear positive for the benefit of their wives. This indicates the value of joint interviews in enabling and supporting those who are suffering from ill health to participate in research interviews but also indicates the way in which joint interviews can influence the construction of the narrative.

Field notes on the general context of the interviews were taken (eg. place of interview and brief impressions of immediate surroundings). The focus of analysis was on the form and content of the interview narrative, however collecting detailed non-verbal communication data in the joint interviews may be important in providing an additional layer of data illustrating the nature and style of interaction between joint interview participants. Future research using joint interviews would benefit from an analysis of non-verbal communication such as symbols, gestures and facial expressions, as recommended by Allan (1980) based on his study of patterns of sociability using joint interviews with married couples.

Using video would provide an additional method of recording both verbal and non-verbal social interaction (Heath, Hindmarsh et al. 2010). Over the past few years video has begun to be used as a method of recording qualitative

interviews. In particular the DIPEX research group at the University of Oxford (now healthtalk.org), have used video to record many interviews focusing on the experience of various health and illness topics, although the aim has not been to analyse data on non-verbal communication. DIPEX has mainly used video to record individual interviews, however some couple interviews have been recorded particularly on the topics of pregnancy, birth and childhood conditions, indicating that the focus has been on experiences in early to mid-life rather than older age.

The importance of focusing on non-verbal data may also be particularly important for participants with speech impairments, such as stroke survivors with aphasia. In a study based on joint interviews with frail older couples (aged 72-96 years) Racher et al. (2000) also collected non-verbal data on interactional patterns. They give an example illustrating the value of this data in an interview with an aphasic stroke survivor with limited speech, and her husband. The interviewer asked the stroke survivor if she was able to write and her husband answered, insisting that she could not write. However she indicated her disagreement by shaking her head and holding up a speech and language workbook. Her husband then said the workbook helps her to write but she has problems remembering things she has learnt. This example also illustrates the issue that spouses may speak on behalf of their partners with speech impairment during joint interviews. In a study based on joint interviews with people with dementia and their informal carers (mainly spouses), Shakespeare (1993) found carers almost ignored the person with dementia but also promoted their competence by 'stealing' the scene to construct the conversation as 'normal', managing a 'spoiled performance' (Goffman, 1963). However in the current study one wife was found to engage in 'scene support' for her aphasic husband, rather than 'scene stealing'.

Although she assumed a dominant role in the narrative she constructed a socially acceptable presentation as a 'united couple', with her husband actively collaborating and inviting her support through his requests for confirmation throughout the narrative. Importantly, joint interviews may offer the opportunity for those with communication problems to participate in research (Sakellariou et al., 2013). For aphasic stroke survivors in particular, having a spouse to support their participation in the narrative may make it easier (as demonstrated in the above example of a wife providing 'scene support') and more likely that they consent to participate in interviews. Jointly interviewing those who are chronically ill and their spouse may make participants feel more comfortable, and it may make it more socially acceptable for the participant with the chronic illness to take rests during the interview (Morris, 2001). However participants may not always feel comfortable discussing certain issues within the context of a joint interview with a partner (Racher et al., 2000) and researchers wishing to use joint interviews should consider the ethical implications in terms of confidentiality. However based on the experience in this study, participants did not appear to share any information during the interview that spouses were not already aware of and most participants appeared very at ease being interviewed together.

The use of joint interviews supports Lawton's call for a shift from the dominance of the single research interview and 'opening the door to a broader range of methods and methodologies to give access to a more broad-ranging and comprehensive picture of individual illness' (2013: 35). This not only applies to the study of health and illness but other areas too, particularly the study of the family, marriage and ageing. This has possible implications regarding the teaching of qualitative interviews in courses on social research

methods. The traditional approach has been to focus on individual interviews, however a consideration of joint interviews as well would broaden the range of methods taught, moving away from a focus solely on the individual's perspective.

Discussion of main findings

Twenty-seven stroke survivors and thirteen spouses participated in interviews. Participants all lived in economically deprived inner city areas, with the majority living in the same area for all of their lives, having raised their families there. Most were from working class backgrounds and had worked in manual occupations. Stroke survivors were aged 75-87, all participants were living with a certain amount of ill health, including stroke and other chronic conditions. A small number of participants were in particularly poor health and appeared to be experiencing a certain amount of discomfort and pain during everyday life.

The time since the participants' stroke ranged from six months to 15 years, although most had experienced their stroke within the last three years. Nine stroke survivors used a stick or a walking frame, six used a wheelchair, and five had mild aphasia. Most participants had children and grandchildren. Many individual participants were widows and widowers who lived alone. Nearly all couples had been married for over 50 years. Overall this group may be regarded as having characteristics reflecting Laslett's (1989) notion of the 'fourth age' as a period of old age characterised by serious illness, functional decline, frailty and physical dependence.

Stroke and self-presentation

The thematic analysis revealed that common experiences and shared sources of identity other than stroke were important in participants' self-presentation. This demonstrates the significance of an individual's whole biography for the meanings they assign to chronic illness, in line with Giddens' (1991) notion of identity as a set of reflexive biographical narratives. Many sociological studies on the experience of chronic illness have tended to focus more on the condition, overlooking other aspects of identity that may be important in contextualising the experience. Although all participants discussed the stroke, three other main overarching themes of self-presentation were identified, namely; work; loneliness and bereavement; and housing and community.

Some participants displayed positive, stoical self-presentations by drawing on past work identities, most notably those from working class backgrounds. Importantly it was not the nature or status of the work that appeared to be of significance but it was the presentation as hardworking, honest and financially self-sufficient. These participants were disassociating themselves from dependence on state welfare and resisting the dominant negative discourses associated with old age and ill health. These were examples of 'moral narratives' providing accounts of changes between the person, the illness and social identity, and which help to (re) establish the moral status of the individual or help maintain social distance (Bury, 2001). They are also examples of a 'capitalist work ethic', the notion that hard work and discipline are duties that benefit both the individual and society, identified by Cornwell (1984) in her study on East Enders' attitudes towards work, health and illness.

The social identities of older people in modern society are dominated by negative images of older people as socially isolated, in poor health and passive and dependent recipients of health and social care services (Victor, 2005). Victor (2005) suggests that these very negative and pervasive stereotypes are evidence of ageism, referring to the systematic stereotyping and discrimination of older people because they are of a particular age (Butler, 1969). Victor (2005) argues that this negative social identity may pervade the personal self-identity of older people who may accept the stereotype of age and become disengaged, passive, grateful recipients of welfare benefits and health and social care services, making the stereotype a reality. Drawing on past work identities appeared to be one way in which participants in the current study resisted this negative social identity of ageing. Rather than passively accepting dominant negative discourses of older age, participants engaged in self-presentation as independent, worthy and hard-working people. Participants did not appear to be attempting to achieve youthfulness on the outer surface through 'masquerade' (Biggs, 1997, 2003, 2005) nor did they appear to be experiencing a 'trapped' self in an ageing outer body, as argued by the 'mask of ageing' theory (Featherstone and Hepworth, 1989, 1995). The present findings support critiques of these two theories for not taking into account the influences of ageism and the stigma of old age (Rozario and Derienzis, 2009). Findings indicate that participants in the present study, who were largely 'fourth agers', were resisting negative social images of old age rather than old age itself. The theories of 'masquerade' (Biggs, 1997, 2003, 2005) and 'mask of ageing' (Featherstone and Hepworth, 1989, 1995) are perhaps more likely to have greater applicability to the experiences of older people in the third age.

Findings indicate that the importance of past work identities for resisting negative social discourses of older age, continues well past retirement into old age. It is possible that past work identities may become more salient in advanced older age when people may be more likely to experience insecurity and uncertainty about their role in a society where identities are strongly linked to the roles of productivity (Phillipson, 1998) and older people tend to be ignored because they are viewed as a non-productive group (Victor, 2005). This was particularly relevant for participants who had previously worked in lower paid jobs who were more likely to experience a lack of financial security in old age compared to those who had been employed in higher paid jobs. It is notable that past work identities were just as important for women as they were for men, with the same number presenting work as a dominant theme (six men and six women). Although the women tended to work in different types of jobs (often related to domestic roles, such as cook, carer, cleaner) to the men (who tended to work in manual jobs) and most of the women had also brought up children, work was as important to them as it was for the men as a means to construct an identity as hard-working, independent and useful. The importance of past work identities in the context of older people's experience of chronic illness has not been focused on in previous studies of this nature.

The experiences of bereavement and loneliness were very significant for some participants' self-presentations, mainly in relation to the death of a spouse. Bereavement and subsequent loneliness were experienced by some as far more of a 'fateful moment' or 'biographical disruption' than the stroke. Bereavement has not previously been described as a 'biographical disruption' but based on the findings I argue that this is a useful way to conceptualise the experience for some, particularly in relation to older people

who have lost a spouse that they have shared their lives with for many years. Findings indicate that the death of a spouse can have a significant and lasting impact on a person's biography, even years after the event, often having a greater impact on biography than the experience of chronic illness, including stroke. Seminal studies conducted over 35 years ago have demonstrated the huge impact the death of a spouse can have on the life course (Elder and Rockwell, 1979) and on social readjustment (Holmes and Rahe, 1967) and this thesis provides up-to-date evidence to support these findings. Participants' experiences were in line with what has been conceptualised as 'emotional loneliness', coming from an absence of a reliable attachment figure and lack of intimate relations, as opposed to 'social loneliness' which relates to an absence of a broad social network or recognised social roles (Weiss, 1973). Some of the participants who described feeling lonely had regular contact with relatives, which supports findings that people can feel lonely even in the presence of others (Victor et al, 2009) and that the quantity of social contacts is less important than the extent to which they meet people's hopes and expectations (Pinquart and Sorenson, 2001). Although the experiences of bereavement and loneliness are not confined to old age, people are more likely to experience the death of a loved one as they age, particularly a spouse who they have shared their life with for many years. This thesis demonstrates the significance of the experience of bereavement and loneliness for self-presentation in older age, which may overshadow other significant experiences, such as chronic illness.

Experiences relating to housing and community were significant for the self-presentations of some participants who had lived on the same council housing estates for most of their lives. Some participants focused on problems with unsuitable housing linked to stroke and other health conditions,

such as poor access for wheelchair users. Participants also focused on the problems they had experienced with their local environment and neighbourhood, including antisocial behaviour and a perceived lack of sense of community. Therefore the stroke was presented as less of a biographical disruption because at the time of the interviews these on-going problems were more prominent in their lives, mainly due to the impact on their finances and quality of life. Participants' narratives also focused on the changes in the nature of their local community that they had experienced over their lifetime. These findings indicate the continuing relevance of Cornwell's (1984) study showing that East Enders romanticised past notions of pre-war social and community life and a sense of a shared experience of poverty while living in housing tenements. This was in comparison to their current living environment, mainly on housing estates built after the Second World War, perceived as less neighbourly due to increased materialism and competitiveness. Despite the current study taking place thirty years later, participants also portrayed similar romanticised notions of the past in relation to a sense of 'community spirit' and good relations with neighbours from a shared social background.

However, since Cornwall (1984) was writing over thirty years ago, other major social changes have taken place that have had an effect on the social and community life of participants. One main change reflected in participants' narratives is the introduction of the 'Right to Buy' scheme in the 1980s by the Conservative government, allowing council tenants to buy their homes. Buying their properties under the 'Right to Buy' scheme led to severe financial difficulties for two participants but also meant that many of the properties in participants' local communities were now owned by private landlords. Overall, the group of participants described a far more transient local

population compared to previous times, seemingly partly due to the short-term lettings of privately owned ex-council properties. They described no longer knowing their neighbours in the way that they had done in the past, partly because they often belonged to very different social groups than the participants (for example, young students and immigrants).

These findings accord with those from a recent interview study of local residents of council housing estates in Bermondsey and Camberwell in Southwark (from a range of ages) (Jensen and Gidley, 2016). Due to the Right to Buy scheme an increase in private renting had occurred over time which resulted in a high level of turnover which led to feelings of alienation among residents. The authors also found that older white participants compared positive memories of the sense of community on estates based on kinship, trust and reciprocity with present feelings of an erosion of local community and an increase in individualism in their local areas that are now run-down, supported by findings from the present study. Data from the 2004 Living in Wales Survey of residents aged 50 and over indicated that with increasing age people are more likely to report dislikes of their neighbourhood due to a lack of sense of community belonging and inclusion (Hillcoat-Nalletamby and Ogg, 2013). This was also expressed by participants in the present study, however all reported that they wished to remain living in their current home with many feeling that they were 'too old' to move from an area where they had lived for the majority of their lives. Hillcoat-Nalletamby and Ogg (2013) also found that the likelihood of wanting to move decreases with age, however those with a long term illness or disability were more likely to contemplate moving, particularly if they felt this had an impact on their ability to remain mobile and autonomous at home. This relates to the experience of one couple in the present study who were the only participants to express a

strong desire to move, due to the husband's poor health and disability as a result of stroke and other chronic conditions which meant their high rise flat could not meet their needs.

Findings have demonstrated the significance of other themes of self-identity in addition to stroke for the participants' self-presentation, suggesting multiple aspects of self-identity. Work, loneliness and bereavement, and housing and community were other dominant themes of self-presentation. Drawing on Giddens' (1991) conceptualisation of self-identity as a set of reflexive biographical narratives, this points to the importance of an individual's whole biography for the meanings they assign to stroke and processes of narrative reconstruction. We now turn to a discussion of the biographical disruptions caused by stroke and the process of narrative reconstruction.

Stroke and biographical disruption

At the time of their interview the narratives of six stroke survivors and one spouse indicate that they had all experienced stroke as a disruption to their biography and therefore their self-identity, mainly due to not being able to continue work or because of the recency of the stroke. Although previous studies have shown that for younger participants with chronic illness work represents normality after illness and returning to work was one strategy used to maintain identity (Charmaz, 1994, Hubbard et al, 2011), importantly this thesis shows that this also extends to older people who are working past retirement age. Participants had also experienced stroke as a disruption due to the effect on their mobility and speech. Their social world had therefore changed and they were no longer able to enjoy the things they used to.

However, whether or not people experienced stroke as a biographical disruption was not related to severity of disability post-stroke.

Four of these six stroke survivors (interviewed two-15 years post stroke) and one spouse engaged in a process of narrative reconstruction as a way to make sense of the stroke and integrate it into their biography and create a sense of order and purpose. These participants drew on different resources to present themselves as positive people, coping with the stroke. For example they talked about their family roles, active roles in the local community and the ability to educate themselves on the causes of stroke and to live healthy lives. This group of stroke survivors narratives were in line with Charmaz's (1987) 'salvaged self' identity level, referring to those who attempt to present themselves to others in a positive light despite the limitations of their illness. However findings indicated no evidence in line with the three other identity levels ('supernormal identity', 'restored self; and 'contingent personal identity') developed by Charmaz (1987). This is likely to be explained by the age of participants as these levels were based on the experiences of younger people with chronic illness, with most aged 40-60 years, and so they had expectations of recreating previous identities ('restored self') or even striving for extraordinary achievements ('supernormal identity'), pointing to the lower health expectations of the older participants in the present study.

For one participant who engaged in a process of narrative reconstruction, his narrative of stroke reinforced his identity as a former trade unionist and campaigner in local politics, reflecting Frank's (1995) 'quest manifesto' illness narrative type characterised by the narrator's desire to draw on their own experience to help others. These findings extend Carricaburu and Pierret's

(1995) notion of biographical reinforcement based on their findings that living with HIV reinforced the identities of haemophilic men and homosexual men. The participant presented a narrative about joining the 'Stroke Governor's Board', at the request of hospital staff, to represent other stroke patients. Even though the stroke had affected his mobility and certain aspects of his life, the narrative of his stroke supported his biography as a trade unionist and supporter of the 'underdog'. Therefore, although the original concept of biographical reinforcement was developed in relation to relatively young men with rare conditions, this thesis has identified the relevance of the concept for people of advanced older age with a far more common condition with sudden onset.

The other two stroke survivors who had experienced the stroke as a biographical disruption did not engage in a process of narrative reconstruction. It is likely that, partly due to the relative recency of the stroke, (six-18 months ago) they were struggling to come to terms with the impact of the stroke on their lives and both were more socially isolated since the stroke and appeared to be quite lonely. It was perhaps too early for them to construct a narrative that attempted to incorporate the stroke within their biography. For the others, who had all had their stroke at least two years ago, they had had more time to adapt and to incorporate the stroke into their identities.

This thesis focuses on a longer period of time post stroke, unlike other biographical studies of chronic illness that have interviewed participants who were newly diagnosed with a chronic condition (for example, Bury, 1982) or up to 24 months post stroke (Pound et al., 1998; Faircloth, 2004). However this is with the exception of Williams (1984) who developed the concept of

narrative reconstruction based on interviews with people who had had rheumatoid arthritis for at least five years. In the present study participants had had a stroke six months to 15 years prior to their interview, with the majority having had the stroke one-three years previously. Some participants may have initially experienced the stroke as a disruption to their identity and biography but had had time to adjust to their changed circumstances after the stroke and engage in a process of narrative reconstruction to incorporate the stroke within their biography and move on. Therefore it is important to acknowledge that the findings focus on one point in time and are partly influenced by the period of time after stroke which supports arguments that the theory of biographical disruption has a temporal element as it was developed in relation to the onset of chronic illness (Delbene, 2011). Over time it appears that stroke has relatively less significance for participants' identity and other aspects take on a greater significance, partly explaining why the other themes of work, loneliness and bereavement and housing and community were more dominant in some narratives.

The majority of participants engaged in self-presentations that were generally positive and stoical, distancing themselves from negative notions of old age associated with ill health and physical dependence. However a group of five participants appeared to be experiencing a certain amount of discomfort and pain due to post-stroke disability and other ill health. This group were all frail and quite disabled after the stroke (three were wheelchair users and two used a stick to walk) and were dependent on others for daily care. Their narratives largely focused on their poor health and hardships of their everyday lives, and they appeared to be 'surviving'. These stroke survivors were less able to engage in lengthy and detailed biographical narratives to make sense of the stroke and did not engage in positive, stoical self-presentations as many of

the other participants did. It could be argued that this group were experiencing the fourth age, in line with Gilleard and Higgs' definition as 'a location stripped of the social and cultural capital that is most valued and which allows for the articulation of choice, autonomy, self-expression and pleasure in later life' (2010: 123). Although the majority of the participants displayed characteristics in line with Laslett's (1989) concept of the fourth age as associated with serious illness and physical dependence, Gilleard and Higgs' (2010) altogether bleaker notion of the fourth age as a social and cultural 'black hole' has greater relevance to this small group of stroke survivors who appeared to be in greater functional decline with little quality of life.

Capturing narrative reconstructions through the method of interviews therefore presents particular challenges. Not only does there appear to be a certain time frame after the onset of illness when participants may engage in a process of narrative reconstruction, but it also depends on participants' current state of health and physical well-being which is likely to be affected by multiple chronic conditions and may fluctuate. The process of narrative reconstruction will also depend on other salient issues in the lives of the chronically ill, as demonstrated by the emergence of themes of self-presentation other than stroke.

In summary, older people engaged in different forms of self-presentation after stroke, although many presented a positive, stoical self, distancing themselves from negative images of old age. Some participants drew on past work identities as a way of emphasising their value as an honest person with a strong work ethic. Other salient aspects of self-presentation were loneliness and bereavement, and housing and community, demonstrating

that over time stroke has relatively less significance for participants' identity and other aspects take on a greater significance. While some participants engaged in a process of narrative reconstruction after experiencing stroke as a biographical disruption others are likely to have had time to adjust to their changed circumstances after the stroke and engage in a process of narrative reconstruction to incorporate the stroke within their biography and move on.

For those stroke survivors who are living as a couple, the meanings and disruptions caused by stroke need to be examined for both the stroke survivor and their spouse together. I now discuss this in relation to the findings from the joint interviews.

Co-construction of narratives by stroke survivors and their spouses

Couples who have been together for many years have shared biographies and therefore intertwined identities. I argue that the meanings and disruption consequent on chronic illness should be considered for both the ill person and their partner, rather than only for each party individually. The experience of chronic illness affects older couples' identities and relationships and so impacts on their health and social care needs. Of the first 12 interviews carried out, two included spouses (who were also informal carers), who played an important role in constructing the narrative. Analysis of these joint interviews raised important issues not only about the experience of spousal caring, but also about how married couples share the experience of stroke, and make sense of it together through their narratives, and the way in which the narratives were co-constructed. Therefore, following a theoretical sampling approach, I began to recruit stroke survivors who were married in order to carry out joint interviews with couples (a method not commonly used

in health research) in addition to carrying out individual interviews with stroke survivors. Taking a dyadic approach, analysis of these interviews focused not only on *what* was said in terms of the content of talk but also on the co-construction of narratives and the style of interaction, in terms of *how* couples talked about and presented events. I drew on a coding scheme designed specifically to analyse interaction between couples focusing on collaborative and conflictual forms of interaction (Veroff et al. 1993).

The three types of co-presentation identified extend current notions of how illness is 'lived' in terms of the daily lives of older couples who have shared their lives for many years. The first type, 'united couple' displayed couples as a team, with partners pulling together to cope with the stroke. Together they constructed an 'idealised front' (Goffman, 1959) emphasising their normality as a couple, despite both spouses often experiencing disability. The second type was the 'positive' carer relationship emphasising the couples' self-reliance, with carers' expressing pride in their role. Both of these types were characterised by a stoic attitude and underpinned by the couple's collaborative style of interaction. Although many of these stroke survivors were physically dependent on their spouse, thus lacking physical autonomy, their co-presentation demonstrated a sense of agency and autonomy as a couple. In contrast the third type of co-presentation, 'frustrated' carer, emphasised the burden of caring for spouses who were also suffering from health problems. This was underpinned by a conflictual style of interaction with the wives tending to dominate the narratives, regardless of which spouse had had the stroke. This may have reflected the general nature of these couples' marital relationships in which the wives took a dominant role in conversational interaction with their husbands. However it is likely that their relationships changed over time and have been shaped by the experience of

the stroke and other ill health for both spouses, with the nature of the marital relationship influenced by illness and disability (Walker and Luszcz 2009).

A review of qualitative studies based on individual interviews has identified carers of stroke survivors as experiencing a loss and change in roles and relationships and in their sense of identity, however this was found to be less applicable to the experience of older carers due to lower expectations or fewer conflicting demands, such as paid employment (Greenwood and Mackenzie, 2010). However the present findings indicate that some older spousal carers do experience a loss and change in roles and relationships and in their sense of identity, particularly within the context of managing their own declining health as well as the co-morbidities of the stroke survivor. The 'frustrated' carers appeared to be struggling to cope with the impact of their partner's stroke and other chronic illness, as well as their own ill health and therefore these couples did not present an 'idealised front' as the other 'united couples' had. The burden of care experienced by the 'frustrated' carers particularly within the context of their own ill health and other issues such as inadequate housing, perhaps meant they were experiencing a threat to their ontological security (Giddens 1991), particularly their psychological integrity, which emerged from the content and style of their narratives. Stereotypical views of old age tend to homogenise older people and thus their role as informal carers (Dean and Thomas 1996), whereas the data demonstrates that older spousal carers are a diverse group within themselves, with differing levels of need; indeed many of the participants would be unlikely to regard themselves as 'carers', particularly those who are part of a 'united couple'.

These findings based on a detailed, systematic and rigorous method of analysis have furthered previous findings focusing on couples interaction in

joint interviews where little detail of analytical methods have been given, implying that findings have not been based on a systematic approach. Previous studies based on joint interviews have identified the largely collaborative nature of interaction (Bjornholtand and Farstad 2014; Sakellariou, Boniface et al. 2013; Torge 2013; and Morris 2001) and Polak Green identified three types of couple interaction; 'Confirmatory accounts' were shared performances where couples echoed each other, reflecting their 'long-established shared way of describing the world' (2015: 8); 'Complementary accounts' were narratives where couples built on and strengthened each other's accounts; 'Contradictory accounts' were narratives where couples challenged and contradicted each other, engaging in negotiation of a shared narrative. In the presenting findings, the 'united couple' and 'positive carer' co-presentations underpinned by collaborative interaction reflect aspects of Polak and Green's (2015) 'confirmatory' and 'complementary' accounts and the 'frustrated carer' presentation underpinned by conflictual interaction reflects aspects of the 'contradictory accounts'. However the present study furthers these previous findings, bringing together a focus on both the content and style of narratives based on two detailed levels of analysis.

There are only a small number of studies focusing on the co-construction of narratives based on joint interviews, although a new literature is beginning to emerge. Drawing on the categorisation of interaction types presented in this thesis (Radcliffe, Lowton and Morgan, 2013), one recent study explores the co-construction of narratives in joint interviews with (non)retired farming fathers (aged 65 and over) and sons in the UK (Riley, 2014). As with the 'united couples' in this thesis, Riley (2014) found a high degree of collaboration between fathers and sons with continual turn-taking and posing

questions to one another, developing the narrative in a process of 'mutually choreographed agreement' (2013: 242). Drawing on the collaborative style discussed in the present study, Riley (2014) identifies the process of 'revelation-through-collaboration' whereby one participant would encourage the other to tell particular stories as part of 'scene-setting', serving as a narrative device for a participant to reaffirm the narrative. He also identifies a process of 'story arching' where father and son worked together to produce a narrative that subtly cast the father in an active role, emphasising past contributions to the family farm, linking them to the present. Both participants would emphasise the advantages of the fathers' continued presence on the farm and participants would often use 'we', presenting the farm work as a team effort, despite the fathers generally lessening their work load as they aged, illustrating a continual process of de-individualising the narrative. This allowed both fathers and sons to distance fathers from the dominant discourse of older age associated with functional decline and a loss of role and identity. Riley (2014) argues that this illustrates the ways in which older age identities are framed in relation to other generations, showing how narratives can be used to script a particular version of the self, with identities (re)produced within the joint narrative.

Riley's (2014) findings demonstrate the relevance of the interaction types identified in this thesis for a different field outside of health and illness. In the present study the 'united couple' and 'positive carer' co-presentations are examples of narratives engaged in a process of de-individualisation. Couples displayed a collaborative 'team effort' to deemphasise the stroke survivors' dependence and the spouses' burden of care. Rather these couples emphasised their sense of autonomy as a couple, distancing themselves from the dominant discourse of age relating to functional decline and loss of

identity. This illustrates the way in which couple identities are (re)produced through co-constructed narratives.

Further analysis of the joint interview data from a sociolinguistic approach provided support for couples' styles of interaction and revealed a further understanding of the way in which narratives were co-constructed, as discussed in the next section.

Sociolinguistic construction of narratives

Building on the previous analysis, an additional layer of analysis was conducted focusing on the sociolinguistic construction of narratives drawing on the systematic and rigorous method of comparative keyword analysis developed by Seale, Ziebland et al. (2006). Analysis focused on differences in narrative construction according to gender, interview context (ie. individual or joint), status as a stroke survivor or spouse, and narrative type, building on previous analysis based on Veroff et al.'s (1993) coding scheme.

Men participated more than women in the construction of narratives during individual interviews contradicting findings from previous studies that women spoke more words and took more turns in individual interviews (Seale, Charteris-Black et al. 2008; Seale and Charteris-Black 2008). One possible explanation could be that in the present study the men in individual interviews were lonelier and did not have as much opportunity to talk with friends and family as the women, who are more likely to have wider social and support networks in old age (Arber and Ginn 2005). These findings support the recommendation that when men's personal experiences of illness are the research topic of interest, it may be better to carry out individual interviews

and to ask questions that maintain a focus on men's, rather than a couple's experiences (Seale, Ziebland et al. 2008).

Individual interviews lasted longer than joint interviews which may be partly explained by the lower levels of social contact of both male and female individual stroke survivors generally, linked with their predominant marital status as widows/ widowers with widowhood consistently linked to the experiences of loneliness and social isolation (Victor et al. 2000). Bereavement and loneliness was a prominent theme for some, as discussed in Chapter Five. Therefore stroke survivors in individual interviews may have taken the opportunity to talk more, constructing longer narratives. This indicates the influence of widowhood, loneliness and social isolation, all associated with older age, on the construction of illness narratives and presentation of self.

In joint interviews women participated more in the construction of narratives, indicating that previous findings based on participants from a range of ages (Seale, Ziebland et al 2008) extend to older age groups. Topics of health and illness are traditionally regarded as topics where women's experiences predominate (Seale et al. 2008) and as participants in the present study were of advanced older age it could be argued that this traditional gender divide is partly reflected in the joint narratives. The present findings indicate that traditional gender differences in language use, such as women's greater use of 'people' words and demonstration of greater emotional expressivity (Boneva and Kraut 2002; Seale, Ziebland et al 2006) and men's avoidance of using the first person as a distancing strategy, demonstrating less emotional expressivity (Charteris-Black and Seale 2009), apply to older age groups. Therefore gender has an important influence on the way in which

older people engage in the construction of narratives to make sense of the experience of illness.

Stroke survivors and spouses participation in joint narratives was relatively balanced, even taking into account that three of the stroke survivors had aphasia. Stroke survivors engaged in a higher proportion of self-presentation than their spouses based on talk about personal experiences, indicating that they were almost equally as active in the construction of joint narratives. This implies that spouses speaking on behalf of participants with chronic illness may not necessarily be a potential methodological challenge to consider for future studies using couple interviews to investigate the experience of illness, depending on the nature of the condition. However it should be noted that in the present study those with severe aphasia were excluded from the sample due to the nature of the biographical narrative interviewing approach, although the sample included five stroke survivors with moderate aphasia. Three with aphasia participated in joint interviews and two in particular (Tony, Tom) valued the presence and support of their wives during the interview. Inviting their wives to comment on or clarify a topic they were talking about appeared to give them a welcome break from talking as well as providing confirmation and support for their narratives. However spouses spoke slightly more words overall possibly due to the poorer health of the stroke survivors, as identified in a joint interview study of people with cancer and their informal carers (mainly spouses) where participants spoke a similar number of words, except where the patient was in poor health (Morris 2001). This indicates that poor health and informal caring roles are likely to influence the construction of illness narratives and presentation of self.

The findings indicate clear differences in joint interviews with older stroke survivors and their spouses according to gender and narrative type supporting the analysis based on Veroff et al.'s (1993) coding scheme (as discussed in Chapter Five). Although women spoke more in joint interviews overall, gender differences in the structure of collaborative narratives were less pronounced, reflecting a more conversational style, and men and women both engaged equally in the presentation of the self. In contrast conflictual narratives were characterised by wives taking a more dominant role speaking much more and engaging more in the presentation of self. The findings that women participated more in joint interviews, particularly in the mainly conflictual narratives, differs from findings of previous sociolinguistic studies that men tend to speak more and more often in mixed sex settings (Woods 1989) and display more 'non-cooperative' language patterns (Coates 2004). This finding also contradicts Manzo et al.'s (1995) argument that wives dominance of conversational interaction with male stroke survivors' was not related to gender. In an interview study of 14 male stroke survivors and their wives (including one with aphasia) they found that stroke survivors lacked agency in interaction dominated by wives but concluded that these findings were not related to gender. However the present findings based on a sample of both male and female stroke survivors and spouses, unlike the sample used by Manzo et al. (1995), indicate that, overall women spoke more and took more turns in joint interviews regardless of whether or not they were the stroke survivor or spouse, and in particular women who were engaging in conflictual narratives were much more likely to take a dominant role in the narrative. This suggests that findings are not only related to gender but also narrative type, rather than status as a stroke survivor or spouse, as Manzo et al. (1995) claimed. As noted, in the current study stroke survivors and spouses spoke similar numbers of words and took similar numbers of turns,

suggesting that rather than lacking agency, stroke survivors were equally active in the co-construction of their narratives together with spouses, even taking into account that three stroke survivors had aphasia. The incorporation of narrative types within the comparative keyword analysis has provided further valuable explanation for differences in the way that men and women engage in the construction of illness narratives.

Wives' dominance in the mainly conflictual narratives may reflect the general nature of interaction in the couples' long-standing relationships, however, as discussed, their relationships and spousal roles are likely to have changed over time shaped by the men's ill health and high level of physical dependency as well as the wives ill health, with the nature of the marital relationship known to be influenced by illness and disability (Walker and Luszcz 2009). In conclusion, the comparative keyword analysis indicates that how people make sense of the experience of illness through the construction of narratives and the presentation of identity is not only influenced by gender, but also interview context (ie individual or joint) and narrative type, within the context of the marital relationship, widowhood, older age and ill health.

Implications for Policy and Practice

In many countries compression of morbidity has not accompanied increasing life expectancy in later life (European Health Expectancy Monitoring Unit 2009). Therefore old age is an important focus for health and social care professionals and policy-makers as the population is ageing and increasing numbers of older people are living and coping with chronic illnesses. A greater number of older spouses will be living with long-term conditions as well as caring for a partner who also has complex morbidities (Pickard et al

2001). Illness and disability do not only affect the individual and their identity but also affect spouses and their relationship and identity as a couple. The relevance of these issues for contemporary society is demonstrated by the appearance of the author on Radio Four's 'Thinking Allowed' programme to discuss findings from the joint interviews based on a publication from this thesis (Radcliffe, Lowton and Morgan 2013).

The heterogeneity and interdependency among older couples in their response to chronic illness needs to be reflected within the context of providing housing, welfare and health and social care to an ageing population. The way illness and disability is experienced and perceived inevitably affects individuals' and couples' health and social care needs, help-seeking behaviour and use of services. The findings have implications in terms of addressing the needs of older spousal caregivers, particularly in relation to the three couples presenting mainly conflictual narratives. The 'frustrated' carers appeared to be struggling to cope with the impact of their partner's stroke and other chronic illness, as well as their own ill health, pointing to a need for practical and emotional support for both marital partners. These findings provide some important contextual insight into the results of a recent UK survey of 2,700 people affected by stroke that revealed two thirds of carers who were spouses or partners experienced difficulties in their relationship with the stroke survivor (Stroke Association 2013). Based on a review of qualitative studies on the experiences of carers of stroke survivors living at home, Greenwood et al. (2009) recommend that researchers move away from simple thematic analysis that emphasises similarities between carers and instead focus on understanding carer diversity in order to provide appropriate support. Through employing the underutilised method of joint interviews with carers and stroke survivors and

the novel method of analysis focusing on interactions between couples as well as content, older spousal carers have been shown to be a diverse group with differing levels of need. Indeed many of the participants would be unlikely to regard themselves as 'carers', particularly those who are part of a 'united couple'. As Torge (2013) points out the policy approach is often to treat the needs of 'carers' or 'patients' as separate rather than focusing on the interrelated needs of the couple. This is an approach promoted by traditional approaches to qualitative interview research which is often constructed from the perspective of the individual. The joint interview findings challenge these traditional care discourses.

Therefore it is recommended that policy on health, social care, housing, and welfare should focus on addressing the interrelated needs of older couples with ill health, rather than continuing to approach needs in relation to the separate and distinct categories of 'carer' or 'patient'. This is in line with recent recommendations of the Stroke Association that carers should be recognised as 'partners in care; and are included in stroke survivor's ongoing stroke journey towards recovery' (2013: 7). This is also reflected in the approach taken by recent UK legislation under the Care Act (2014) aiming to put 'carers on an equal footing to those they care for and putting their needs at the centre of the legislation' by offering all carers a needs assessment (Department of Health, 2013). Government and charitable organisations have previously tended to approach carers as a homogenous group but these recent policy documents indicate a move towards recognising the heterogeneity of carers and their interrelated needs together with those they care for.

Health and social care services also need to be more integrated to be able to address the interrelated needs of couples and families coping with chronic conditions. Findings suggest that rather than health and social care services focusing on an individual's single condition, such as stroke, patients' needs would be more likely to be addressed by not only focusing on a person's co-morbidities, but also the interrelated needs of couples and families. For older couples in particular, it can be common for both spouses to be living and coping with multiple chronic conditions and supporting each other in this. This supports arguments that health and social care services need to be more joined up (Smith 2013). This is an approach that has received much attention recently, with the government aiming to deliver joined up and coordinated health and community care services by 2018 ('Integrated Care: Our Shared Commitment', Department of Health, 2013). The prime provider model is one model that aims to integrate services across a pathway. Some Clinical Commissioning Groups are beginning to use this model for a number of services across the UK (Illman and Williams, 2013). This involves commissioning one lead organisation to manage and take responsibility for a whole pathway through subcontracting work to other providers, with a proportion of payments dependent on the achievement of specific outcomes (Warren, 2013; Illman and Williams, 2013). The prime contractors are expected to demonstrate their involvement of service users, carers, clinicians, and the community in any changes and improvements (Warren, 2013). Although this model aims to integrate services across whole pathways it is not yet clear how the needs of patients with co-morbidities would be addressed.

Within the context of the policy of 'ageing in place' promoted by the UK Government, greater access to specialist support and advice, and

improvements to mainstream housing as well as local environments are recommended to enable older people to continue to live in their own homes as they age. The importance of housing and community in the narratives of some participants who had lived on the same council housing estates for most of their lives, links to the wider social and policy issue of ageing in place. Ageing in place has been a 'seamless and almost endless policy commitment' since the 1940s (Means 2007: 67), however since the late 1980s there has been criticism of community care policies for their lack of focus on housing. Findings lend support to arguments that existing mainstream housing for older people needs improving, especially for those on low incomes, and greater investment is needed in a much wider range of specialist support and advice services (Means, 2007). The majority of participants indicated that they wanted to 'stay put' and age in place supporting other research findings that the vast majority of older people value 'ageing in place' ('Global Age-friendly Cities: A Guide', WHO, 2007). However, drawing on data from the 2004 Living in Wales Survey and a critical review of the literature, Hillcoat-Nalletamby and Ogg (2013) argue that older people's level of satisfaction with where they live should not be viewed uncritically as a premise for policy makers to promote ageing in place. Despite the majority expressing a desire not to move, many participants in the present study expressed dislikes with their neighbourhood, mainly due to a lack of sense of community, antisocial behaviour and a poorly maintained local environment. Therefore as well as improvements needed to older people's housing, this points to important issues with older people's local environment that need to be addressed within the context of ageing in place, particularly in relation to older people from low-socio-economic and vulnerable groups living in social housing.

Older people, including older carers, who wish to continue to work past retirement age should be supported and encouraged to do so where possible. For example employers could provide greater flexibility in terms of part time working for older people or job-sharing, or perhaps develop more mentor-type roles for older people aimed at sharing experience and knowledge with younger, less experienced workers. The findings demonstrate the continuing relevance of work for the positive identity of older people, with participants drawing on past work identities to present themselves as useful, hardworking and financially independent. Where possible, supporting older people and older carers to continue to work past retirement age, for those who wish to, would not only provide vital financial support in older age but also contribute to a positive sense of personal identity and self-worth. Employment may also provide valued social contact and social relationships, decreasing the likelihood of loneliness and social isolation which is more common in older age. The provision of support to remain in paid work, along with support to participate in social activities and support with household tasks, are important for people who experience illness as a threat to their identity Hubbard et al (2010). Biographically informed care could help chronically ill people to retain previous identities and also develop new identities in the context of changed circumstances (Hubbard et al., 2010).

In addition to addressing needs in terms of wider housing, welfare, health and social care policy, discussed above, engaging in a process of narrative reconstruction may be an additional tool that could be used by health and social care professionals to facilitate and encourage resilience amongst older people with chronic illness. A mixed methods study found that the process of narrative reconstruction was an essential strategy for older people in developing resilience in the face of adversity because it enabled people to

maintain a sense of identity and give meaning to adverse experiences (Hildon et al, 2008). This is supported by a review of qualitative studies on adjustment post stroke that identified the importance of narrative reconstruction as a resilience practice and that the interview process is helpful in this respect (Sarre et al., 2014). The current findings indicate that, despite the experience of the stroke and other hardships in life, those who engaged in narrative reconstruction during the interview to make sense of the stroke and incorporate it into their biography certainly presented themselves as more stoical and resilient compared to those who did not engage or had not yet engaged in a process of narrative reconstruction.

Recommendations for further research

The multiple layers of analysis used for joint interview data has enabled a detailed understanding of the different ways in which older couples who have been married for many years interact with each other and participate in the co-construction of narratives to make sense of the experience of stroke. These findings show how older men and women engage in the process of narrative reconstruction after illness to incorporate it within their shared biographies. As clear differences in narrative construction have been found based on gender and narrative type, it is important that researchers carrying out joint interviews in future should pay attention to gender differences in how much participants speak and how often as this will have an impact on the nature of the data produced. The three narrative styles are recommended as a tool to identify and categorise any differences in participation in the narrative based on Veroff et al.'s (1993) coding scheme.

The findings of this thesis have begun to address the gap in sociolinguistic studies focusing on both gender and older age, particularly in relation to older people who are frail, in poorer health and more marginalised. Further research using comparative keyword analysis could provide more insight into gender differences in individual and joint interviews, particularly regarding findings that joint interviews resulted in a degree of gender convergence, based on a reduction of women's references to emotions and social networks in joint interviews compared to individual interviews (Seale et al., 2008). Therefore further analysis could focus on the number of 'people' words (eg. neighbours, daughter, son, sister, friend) and the number of 'feelings' words used by women and men (eg. felt, coped, nervous, accept, confidence).

No sociolinguistic studies have been identified that include people with aphasia. It is recommended that further research is carried out focusing on people with aphasia, drawing on the comparative keyword analysis approach. Although the current findings showed no significant differences between the amount of words spoken or turns taken between spouses who had aphasia and those who did not, the use of 'people' words or 'feelings' words may differ, and so too may the type and complexity of other vocabulary used. Further research focusing on the interaction between couples in joint interviews where one participant has aphasia may also build on the present findings, providing important insights into the communication patterns of aphasic people and the ways in which spouses may attempt to support or perhaps dominate communication. There are likely to be differences in interaction between spouses depending on the type of speech impairment; dysarthria is characterised by slurring or thickness of ordinary speech and expressive dysphasia is characterised by difficulty finding the right words to express thoughts. Further research would contribute to an understanding of how

spouses may provide 'scene support', as identified in the interactions of one couple in the present study where the husband had moderate expressive dysphasia, or how spouses may engage in 'scene stealing' as a way of managing a 'spoiled performance' (Goffman, 1963), as identified based on joint interviews with people with dementia and their informal carers (Shakespeare 1993).

Further studies are also needed to examine variations in the content and style of interaction that may occur between couples and other family members at different stages of managing the demands of chronic illness and disability and for different age groups, socio-economic, ethnic and cultural groups. Further longitudinal research is recommended to provide a greater understanding of the different stages of managing the demands of chronic illness and its impact on identity. As stated, the majority of stroke survivors in the present study had experienced their stroke between one to three years before the interview and therefore had time to adjust to changed circumstances. Longitudinal research involving joint interviews carried out at different time points after chronic illness to track the adjustment process for couples would provide valuable data. In particular it would be useful to focus on how couples approach and make sense of any changes in spousal roles over time, such as the transition from spouse to 'carer' and whether the style of narrative reflects a process of adjustment or whether more time living and coping with chronic illness may perhaps lead to greater underlying tension in couple's narratives, exacerbated by the declining health of both spouses. Conducting longitudinal research based on participants with other chronic conditions would be useful in understanding the trajectory of managing and adjusting to conditions that differ from stroke, particularly in their onset. For example arthritis, diabetes or a heart condition are likely to be much slower in their

onset than the sudden onset of stroke, which may lead to differences in the process of incorporating the illness within a person's or couple's identity through narrative (re)construction.

Based on the findings it is recommended that the SLSR team considers collecting routine data on participants' marital status, whether or not participants have a main informal carer, the relationship to the carer and carers' health status. This may be useful in providing data on the prevalence of informal carers for stroke survivors and the nature of relationships with carers and an understanding of carers' health, contributing towards an approach that considers the impact of stroke on relatives, as well as the individual, and also the interrelated needs of both stroke survivors and carers.

A large proportion of the population live as a couple, with just over half of adults in the UK living as married or cohabiting couples in 2011, and 56% of over 65s living as a couple (Office for National Statistics, 2013). Nearly three quarters (72%) of UK households were made up of two or more people in 2014 (Office for National Statistics, 2014). Joint interviews are recommended as an ideal method for future research relating to couplehood, whether amongst older or younger age groups, on topics relating to family, marriage, social networks, caring, disability, health and illness. Joint interviews are an ideal method for studying 'family display' (Bjornholtand and Farstad 2014) referring to 'the process by which individuals and groups of individuals convey to each other and to relevant audiences that certain actions constitute 'doing family things' and thereby confirm that these relationships are 'family' relationships' (Finch, 2007: 67). The concept of 'family display' (Finch 2007) emphasises the social nature of family practices, where the meaning of a person's actions has to be both conveyed to and understood by others

through social interaction so as to be effective as constituting family practices. Based on the present study, it is suggested that joint interviews could be further developed to also include other family members to study identity in action within a family context. The value of the data would be in the pre-existing relationships between participants therefore this would differ considerably from focus groups where participants would not normally know each other.

Conclusion

This thesis has examined the experience and meaning of stroke in relation to the self-identity of people aged 75 and over, based on a biographical-narrative approach. It has drawn on both Giddens's (1991) conceptualisation of self-identity as a set of reflexive biographical narratives and Goffman's (1959) notion of identity as constructed in everyday social interaction. An original, systematic and practical method of analysis has been employed, based on three different forms of analysis of a single dataset. Biographical narrative interviews were carried out with individual older stroke survivors as well as the underutilised method of joint interviews with both stroke survivors and their spouses. The approach to analysis of joint interviews was particularly novel, focusing not only on *what* was said in terms of the content of talk but also on the co-construction of narratives and the style of interaction, in terms of *how* couples talked about and presented events. Findings of the comparative keyword analysis and the coding of couples' interaction provided support for one another, further validating the methods.

Findings demonstrate that multiple aspects of self-identity are important in stroke survivors' self-presentations, particularly the continuing relevance of

work. Participants drew on past work identities to present themselves as useful, hardworking and financially independent, resisting negative social identities of older people as socially isolated, in poor health and as dependent recipients of benefits and services. The importance of past work identities in older age has not been identified in any previous studies of this nature. The experiences of bereavement and loneliness were very significant for some participants' self-presentations, mainly in relation to the death of a spouse. Bereavement and subsequent loneliness were experienced by some as far more of a 'fateful moment' or 'biographical disruption' than the stroke, which has not been identified in other studies on older people's experience of chronic illness. Housing and community were significant aspects of self-presentation for some participants who had lived on the same council housing estates for most of their lives. Some focused on their experience of problems with unsuitable housing linked to stroke and other health conditions, such as poor access for wheelchair users. Others focused on the changes they had witnessed in their local environment over their lifetime and the problems in their neighbourhood, including antisocial behaviour, and the perceived erosion of local community. The significance of themes of self-presentation other than stroke point to the importance of an individual's whole biography for the meanings they assign to stroke and processes of narrative reconstruction.

The period of time after stroke had an important influence on the findings, supporting arguments that the theory of biographical disruption has a temporal element as it was developed in relation to the onset of chronic illness (Delbene, 2011). This thesis focuses on a longer period of time post stroke (six months-15 years), unlike other biographical studies of chronic illness that have interviewed participants who were newly diagnosed with a chronic

condition (for example, Bury, 1982) or up to 24 months post stroke (Pound et al., 1998; Faircloth, 2004). Stroke was experienced as a biographical disruption by some participants mainly due to the recency of the stroke or inability to continue work, but this was unrelated to severity of disability post-stroke. A number of these participants (interviewed at least two years post stroke) engaged in a process of narrative reconstruction as a way to make sense of the stroke and integrate it into their biography and create a sense of order and purpose. Other participants may have initially experienced the stroke as a disruption to their identity and biography but had time to adjust to their changed circumstances after the stroke and engage in a process of narrative reconstruction to incorporate the stroke within their biography and move on. Therefore over time it appears that stroke has less significance for participants' identity, partly explaining why the other aspects of work, loneliness and bereavement and housing and community were more dominant in some narratives.

Findings have demonstrated that illness and disability do not only affect individuals and their identity but also affect spouses and their relationship and identity as a couple. The joint interviews revealed three types of co-presentation that extend current notions of how illness is 'lived' in terms of the daily lives of older couples who have shared their lives for many years. 'United couple' displayed couples as a team, with partners pulling together to cope with the stroke, emphasising their normality as a couple, despite both spouses often experiencing disability. The second type was the 'positive' carer relationship emphasising the couples' autonomy despite stroke survivors' physical dependence on their spouse, with carers' expressing pride in their role. Both of these types were characterised by a stoic attitude and underpinned by the couple's collaborative style of interaction, demonstrating

a sense of agency as a couple, distancing themselves from the dominant negative social identities of older people related to poor health and physical dependence. In contrast 'frustrated' carer presentations emphasised carer burden for spouses with their own health problems, underpinned by conflictual interaction with wives taking a dominant role in the narrative. The findings have shown the ways in which couple identities can be (re)produced through co-constructed narratives. It is likely that couples' relationships changed over time, shaped by the experience of the stroke and other ill health for both spouses. Findings challenge traditional care discourses treating the needs of 'carers' or 'patients' as separate rather than focusing on the interrelated needs of the couple. The heterogeneity and interdependency among older couples in their response to chronic illness needs to be reflected within the context of providing health and social care to an ageing population.

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Appendices

Appendix A: Invitation letter

Appendix B: Information sheet

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Appendix I: Conference papers and media resulting from this study

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Appendix A: Invitation letter



University of London

Date _____

Dear _____

I am writing on behalf of a PhD student at King's College London who is conducting a study to examine the experience of stroke in relation to identity.

As you are aware, you are registered on the South London Stroke Register data base and we are writing to ask if you might be willing to help with a research study. This will involve meeting with a researcher who will discuss with you your experience of stroke and other important aspects of your life that may relate to your stroke. If you wish you may have a relative or friend present at the interview with you.

We enclose a brief explanation sheet about the study. If you would be interested in taking part please complete the reply slip below and post it in the prepaid envelope provided and the researcher will contact you shortly. If you have any queries please contact the researcher, Eloise Radcliffe, on 0207 848 6638.

With many thanks
Yours sincerely

A handwritten signature in black ink, appearing to read 'Charles Wolfe', with a long horizontal flourish extending to the right.

Professor Charles Wolfe
Director
South London Stroke Register

I would like to take part in the interview study on the experience of stroke.

I wish to have a relative or friend present at the interview **Yes** / **No**
(please circle)

Name.....

Telephone Number.....

Address.....

.....

Signature.....

Version 1: 19/12/07

Appendix B: Information Sheet



University of London

Patient Information Sheet

Interview study: stroke in a biographical context

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives, and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is undertaking the study?

The study is being undertaken as part of a PhD project at King's College London.

Why is the study being undertaken?

The aim is to understand experiences of stroke in relation to other aspects of life.

What will the study involve?

We are inviting people who are listed on the South London Stroke Register to participate in an informal interview. This will involve meeting a researcher who will ask you some questions about these main areas:

- How your experience of stroke relates to other aspects of your life.

- Any other important events that may have occurred recently in your life, such as other health problems.
- The ways in which your life may have changed since you had the stroke.

A relative or friend may be present at the interview if you wish.

What happens next?

A researcher will contact you and will discuss the study and answer any questions. Participation would involve talking with the researcher at your home at a time and date convenient to you. The informal interview will take 30-90 minutes and will be tape recorded to assist the researcher. If you decide to take part everything you say will be treated confidentially and no information will be provided to health service staff. You are also free to withdraw from the interview at any time and without giving a reason. A decision to withdraw or not take part will not affect the standard of care you receive.

What happens to the results?

The results of the study will be published and you are welcome to receive a copy. No individuals will be identified in any report or publication.

Thank you for considering taking part in this study.

Contact for further information: Eloise Radcliffe Tel: 020 7848 6638

Dr Myfanwy Morgan Tel: 020 7848 6641 (Supervisor)

Version 1: 11th Dec 2007

Appendix C: Consent form



University of London

Consent form

Title of Project: Stroke and self-identity

Name of researcher:

Patient identification number:

1. I confirm that I have read and understand the information sheet dated 11th December 2007 (version 1) for the above study and have had the opportunity to ask questions.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

3. I am willing for the interview to be recorded.

☐

4. I agree to take part in the above study.

☐

Patient name

Date

Signature

Researcher

Date

Signature

Version 1: 11th December 2007

Appendix D: Topic guide

Study title: Stroke and Self-identity

Broad topic guide

Initial question:

I am interested in the stories of people with stroke. Please tell me the story of your stroke, anything that occurs to you. You have as much time as you like. I won't ask you any questions for now. I will just make some notes on things that I would like to ask you more about later.

Additional questions/ prompts:

Can you tell me about what happened when you had the stroke?

Do you feel your life has changed since you had the stroke?

Tell me about how your life has changed since you had the stroke?

How was your life before the stroke?

How has your life been after the stroke?

Do you feel you have changed since you had the stroke?

Can you tell me about any problems you've experienced since the stroke eg. in getting around?

Version 1: 04.01.0

Appendix E: Letter of approval from the Research Ethics Committee

Bromley Local Research Ethics Committee

Bromley PCT, Bassetts House,
Broadwater Gardens
Farnborough
Kent
BR6 7UA

Telephone: 01689 880592
Facsimile: 01689 855662
29 February 2008

Ms Eloise Radcliffe
PhD Student/Research Associate
Kings' College London
Capital House
42 Weston Street
London SE1 3QD

Dear Ms Radcliffe

Full title of study: **Stroke and self-identity among people of
advanced older age: A biographical approach**
REC reference **08/H0805/5**
number:

The Research Ethics Committee reviewed the above application at the meeting held on 21 February 2008. Thank you for attending to discuss the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation. However, you are requested to note the following:

- the tapes of the interviews should be retained as raw data and these should be stored securely and in an anonymised form;

- the study title in the invitation letter to stroke patients is incorrect and should be amended;
- in the principal exclusion criteria at question A23 the description 'those not alert' should be replaced by the description 'those lacking capacity', and formal tests for mental capacity should be used in these circumstances;
- the question 'Tell me about why you think you had a stroke?' on the interview Topic Guide should be reworded to make this more explicit;
- references to CERES should be removed from the Information Sheet for Patients as this organisation no longer exists.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application		08 January 2008
Investigator CV		03 January 2008
Protocol	1	07 January 2008
Covering Letter		10 January 2008
Interview Schedules/Topic Guides	1	04 January 2008
Letter of invitation to participant	1	19 December 2007
Participant Information Sheet	1	11 December 2007

Participant Consent Form	1	11 December 2007
Honorary Contract for CI		19 May 2006
Letter to GPs	1	11 December 2007
Academic Supervisor's CV		08 January 2008

R&D approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final approval from the R&D office for the relevant NHS care organisation.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

Here you will find links to the following

- a) Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service on the application procedure. If you wish to make your views known please use the feedback form available on the website.
- b) Progress Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- c) Safety Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- d) Amendments. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

- e) End of Study/Project. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nationalres.org.uk .

**08/H0805/5
correspondence**

Please quote this number on all

With the Committee's best wishes for the success of this project

Yours sincerely



**Ms Carol Jones
REC Chair**

Email: janine.peters@bromleypct.nhs.uk

Enclosures: List of names and professions of members who were
present at the meeting and those who submitted written
comments
Standard approval conditions

Copy to: *Karen Ignatian, R&D Office, Guy's and St Thomas's
NHS Foundation Trust*

Appendix F: Synopses of interview participants

Individual interviews

ID1, 22.11.07, Rose (pilot interview)

Rose (white British, aged 84) had the stroke 18 months ago in the middle of the night after she went to the bathroom and then collapsed by her bed as her left side was paralysed. Her two daughters were staying with her at the time and she called for them and they called an ambulance. She had received thrombolysis treatment in hospital which she described as 'a miracle', as she felt she had largely recovered from the stroke as a result, although she felt more tired. She had a son and two daughters and grandchildren, some of whom lived nearby.

A few days before her stroke, her daughter had died after being ill in hospital. She attributed her stroke to the shock of her daughter's death. She became upset while talking about this and after a break we resumed the interview.

Rose is a widow and lives alone in a ground floor council flat. She has a son and a daughter and a granddaughter who live in another county and a granddaughter and great granddaughter who live nearby. Her granddaughter helps her with housework and shopping. She had previously worked as a bookkeeper. She is able to walk short distances but has some difficulty with this.

ID2, 23.11.07, Bob (pilot interview)

Bob (White British, aged 87) had had his stroke six months ago while on his way home from work. He was getting off a bus intending to stop in at a local supermarket on his way home and described 'not feeling well at all' so he asked a man to call an ambulance which took him to hospital. When he did not arrive at work the next day a colleague called his home and then the local hospitals when he did not answer. When she found out he was in hospital she informed his only son who lived a couple of hours drive away. He was in hospital for three months after this.

Bob is a widower and lives alone in a first floor flat rented from a Housing Association. He has a son who is divorced and a grandson he rarely sees. His son comes to visits him weekly to stay for the weekend. Bob had been working part time in a concierge-type role on a front desk for a large national company before he had the stroke. He had been in this part time role for 22 years, after he had initially retired from his full time job at the age of 60. He has limited mobility and uses a stick indoors and does not walk outside. His neighbour brought him a paper on most days. He talked a lot about wanting to try to walk outside alone which he had not done since the stroke. He said his son thought he not recovered enough to do this.

ID3, 3.3.08, Mary

Mary (White British, aged 75) was at home when she had the stroke seven years ago and her teenage granddaughter was staying with her at the time. She described feeling 'disorientated' and 'all twisted' on the sofa and making her way to the kitchen to bang on the wall so that her granddaughter would come from the bedroom, but she could not hear at first as she was listening

to music using headphones. Her granddaughter called an ambulance and Mary described being delirious when she first arrived at the hospital, where she stayed for two weeks.

Mary talked about sister who had had a heart attack just before Mary had had her stroke and attributed her stroke to the stress of travelling to her sister's house in another county to help her husband-in-law while her sister was in hospital. She described falling out with her sister after this and said they no longer speak as they are 'chalk and cheese'.

Mary is a widow who lived alone in a ground floor council flat. After initially being 'forced' to retire at 60 from her job in call centre, which she experienced as a 'shock', she had then taken on regular cleaning and babysitting jobs for families and had really enjoyed this work. However after her stroke she had had to stop working as her eyesight had been badly affected. She described initially bumping into furniture when she came home from hospital and said she often needs to ask people to help her cross the road. She said she like to be as independent as possible though by going out alone and not relying on family members. Her daughter is currently receiving treatment for cancer so she tries to go to her daughter's house by bus as often as she can and help with housework such as ironing.

ID5, 22.7.08, Tim

Tim (White British, aged 75) had a stroke two years ago. He was getting ready to go his regular cycling session at a local velodrome when he 'suddenly felt something was happening in my, around my eyes' and he realised he was having a stroke. He called his wife and she called an ambulance. He was taken to hospital where he received thrombolysis. He felt he had made a good recovery and joined the 'Stroke Governor's Board' of the hospital as he felt it was important that he was speaking from experience and representing other stroke patients. He is able to walk but has some difficulty and could no longer being able to do many things that he used to enjoy such as cycling and DIY.

Tim is married and lives with his wife (his second marriage) in a house that they own. He has an adult son and daughter. He was an electrician and a trade union representative, and had retired at 60. He had been involved in local politics before his stroke.

ID8, 12.1.09, Leonard

Leonard (Black Caribbean, aged 80) had his stroke 18 months ago. He came home from work and his wife said he looked unwell so she called the doctor and they phoned for an ambulance. He was in hospital for 9 days and was told that he had had 2 strokes. He was able to walk slowly with a walking frame and his speech was slightly slurred.

Leonard worked as a carpenter and was from Jamaica. He lived in a council flat with his wife (second marriage). However he said that his wife (also from Jamaica) did not spend much time at home and did not help him at all since the stroke and he was planning on speaking to a lawyer about a

separation. He had four children from his previous marriage, one lived in the UK, one is Jamaican and two live in America as well as some of his siblings and cousins. He said he was planning a trip to visit them as soon as he could save enough money. He had daily help from a carer.

ID9, 12.1.09, Paul

Paul (Black Caribbean, aged 79) had his stroke 18 months ago. He had just returned from a holiday in Barcelona and when he got up the next morning he felt weak and unwell and called an ambulance. He had some physio in hospital and returned home able to walk with a stick and was able to walk to the bathroom. Shortly after this he was unwell again and became unable to walk. He had carers to help him twice a day. He lived in a ground floor council flat but had been unable to leave his flat since he came home from hospital after stroke. He was severely disabled and had a hospital bed in the living room with a hoist. He had a bathroom that had been converted for wheelchair use. He had lost the use of his legs and could only sit up on his bed with help. He had lost the use of his left side but could feed himself using the right hand. He had moderate aphasia ie. some stammering and difficult with findings the correct word.

Paul was from Trinidad. His wife had died in the 1980s and he had a daughter who lived in Trinidad. He had worked as a delivery driver. Before his stroke he had liked to travel. He liked to listen to the radio and watched TV.

ID12, 19.7.09, Delia

Delia (White British, aged 75) had a stroke 18 months ago. She had had major dental surgery to have tooth implants and the surgeon had found that she had a 'nasty abscess' and she described a lot of bleeding but said she felt no pain as the 'nerve of the tooth had been killed'. A week after the surgery she had to have the stitches out and it was then that the stroke began with feeling very tired and a 'massive headache'. She said she thought she was going to die. After she had managed to get home on the train she called one of her daughters and ex-husband, who was a friend, and they called a GP who visited her at home. She told him what was wrong and he examined her and said he was 'puzzled' and 'walked away'. She called her dentist who 'said it's not his fault'. Two days later they called another GP who recognised that she had had a stroke and told her to go to hospital immediately.

Delia lived alone in a house that she owned. She used to be a painter and art teacher. She had recently acquired two new art students but said she had not done any painting since the stroke. She felt her life had changed a great deal since the stroke and although she could walk unaided, she could no longer walk as far and do everything she used to and got tired more easily and her vocal cords had been affected. She had been married and divorced twice and had three daughters and grandchildren. She felt they did not really understand how she felt different since the stroke. She enjoyed going out with friends to the theatre before the stroke but found this difficult now. She still saw friends and had recently taking up piano lessons to keep her mind active.

ID14 22.8.10, Alfred

Alfred (White British, aged 84) had a stroke two years ago. When he first came out of hospital he had received physiotherapy and help from paid carers for a few weeks. He could walk slowly unaided but used a stick to walk outside.

Alfred was a widower who lived alone in a ground floor council flat. His wife had died ten years ago. He had four daughters and grandchildren and great grandchildren who lived nearby with whom he had a good relationship and saw them regularly. He had three daughters who helped with shopping etc and who he saw regularly and a son who had passed away ten years ago in a car accident. He had been a lorry driver before he retired. He went out for a walk every day to get a newspaper and carried on in his hobbies of painting and making model aircraft.

ID20, 24.9.09, Joan

Joan (White British, aged 79) had a stroke nearly two years ago. She was unwell and was admitted to hospital where she was diagnosed with a stroke. She gradually regained her speech and physical ability but she could not walk far after the stroke and used a stick. She went to the local shops but did not go out any further than that by herself. She feels she has got stronger since the stroke and was having more physiotherapy soon. She also had diabetes and pain in her hip due to osteoarthritis.

Joan was a widow who lived alone in a high rise maisonette rented from a Housing Association. Three months after her stroke her husband had become ill with a heart condition and she had cared for him at home for six months before he died. She had three children (one daughter lived abroad) and grandchildren but she did not see them that often as they did not live nearby. She had problems using the stairs and would like a stair lift but the housing association would not let her fit one.

ID31, 6.8.10, Derek

Derek (White British, aged 77) had the stroke five years ago. While he was shopping and picked up a jar and dropped it because he could not grip it as his arm and hand were partially paralysed. He already had an appointment with his GP in the afternoon so when he told his GP he was sent straight to hospital. He had largely recovered physically from the stroke and was able to walk and drive but described feeling very emotional since his stroke. He was taking warfarin and also had diabetes and respiratory problems.

Derek was a widower who lived alone in a council flat. He had a daughter and granddaughter whom he saw quite regularly even though they lived two hours drive away. His wife died ten years ago and he had stopped work to care for her at home while she was ill with emphysema for five years.

ID 3, 17.8.10, Sheila

Sheila (White British, aged 86) had a stroke five years ago. She had previously had many health problems and so she said the stroke was not a great shock and she 'got on with it'. Arthritis in her spine was her main health problem that she had had from an early age this affected her walking.

She was able to walk very short distances. She was very articulate but had a few problems remembering events and repeated herself a few times.

She was a widow who lived alone in a sheltered housing flat. She had no children but was close to her daughter-in-law (married to her husband's son). She married 'later in life' in 1968 in her 40s. Her husband was a widower who had 10 children. He was a dock worker and died in a dock accident in 1987 so she said she was used to problems in her life. She had worked for the majority of her life and travelled a great deal. She had worked as a Land Girl on a farm on the Isle of Wight during the Second World War and she lived and worked in Australia for six years, returning in 1960. Her last previous job was as a bookkeeper. She had been a local councillor for 8 years (1994-2002) retiring when she was 78 years old although the official retirement age was 65.

ID 26, 5.8.09, Martha

Martha (originally from the Czech Republic, aged 79) had originally had a stroke 20 years ago after dental surgery and although this was not diagnosed at the time she feels very strongly that in the light of two transient ischemic attacks and another stroke over the previous two and half years, it had been a stroke. She was in hospital for two nights after the most recent stroke. She experienced some difficulty moving around but was able to walk unaided. She had aphasia and so sometimes got words mixed up and spoke in quite a slow stilted manner, appearing to think about many of her words before she spoke them.

Martha was a widow who lived alone in a first floor flat that she owned. She had previously worked as an editor and manager in education and

publishing before retiring. She had a daughter and two teenage grandsons who she saw quite regularly. She attended a local over 65s group and a service user group and talked about the importance of engaging in 'brain-training' activities. She talked about not wanting to be a 'burden' on her family and her 'do not resuscitate' pendant she wore.

ID 27, 17.8.09, Gloria

Gloria (Black Caribbean, aged 81) had a stroke 18 months ago. She had called her sister when she felt unwell and they had called an ambulance and she had stayed in hospital for 3 weeks. She was not able to walk very well since the stroke and used a stick and said she was stiff and in quite a lot of pain. Since the stroke she was no longer able to go out and do her shopping. She also had arthritis, asthma. She was originally from Jamaica lived alone in a council flat. Her husband passed away two years ago after a 'liver problem' and she had cared for him at home. She had a sister, a niece and a friend who sometimes helped her but had no children. She talked a little bit about her religious beliefs helping her cope. She had worked as a part time cleaner before retiring.

ID 28 21.10.09, Ethel

Ethel (White British, aged 75) had a stroke three years ago while she had been hanging out washing in the back garden and a neighbour who lived in a flat above her saw her collapse and called the emergency services and the police had to break her door down so ambulance staff could get in. Ethel questioned whether she had actually experienced a stroke as she felt the symptoms were more likely to be due to all of the strain she had been under before her stroke as her husband had died shortly before this and she had

been experiencing numerous problems with housing and anti-social behaviour. She talked about the frequent harassment she had experienced from local youths over the last few years and how they would throw stones and bricks at her windows and patio doors. She felt that they were targeting her because she was an 'old person'. This situation became particularly bad during the three week period that her husband was dying at home due to 'diabetes' and an 'enlarged heart'. Ethel also had Arthritis, a heart problems, a thyroid condition and used a pram to help her walk when she went out as she did not like using a walking frame.

Ethel was a widow who lived alone in a ground floor flat that her and her husband had purchased under the right to buy scheme. She talked a lot about the financial difficulties she had experienced as a result of buying the flat. She had no hot water, no electricity and her flat was very dirty and untidy. She had children and grandchildren who lived nearby who helped her. She appeared very angry and frustrated about certain events that had happened to her.

Couple interviews

ID11, 9.1.09, Patrick and Betty

Patrick (White Irish, aged 85) experienced his stroke at 5am in the morning and he had fallen in the bathroom and his wife, Betty (White British, aged 83), had called an ambulance. The stroke had left him deaf in one ear but he was still able to walk unaided although he could not walk as far since the stroke and was not as active as he had been before although he still went out to get the paper everyday. Betty had osteoporosis and had had a few falls but she was able to walk unaided. They did not have children and had no close living relatives. Patrick had worked at the docks as a shipbuilder and then as a van driver for the local council before he retired and Betty had worked in a bookmakers as a cashier before she had retired. They had bought their council bungalow under the 'Right to buy' scheme and were experiencing financial difficulties as a result. They had been married for 58 years and had lived in the same home for the nearly all of their married life.

ID13, 26.1.09, Jack and Penny

Jack (White British, aged 79) had a stroke just over a year ago when he tried to get out of bed in the morning and collapsed. His wife Penny (White British, aged 59) called the ambulance and he spent six weeks in hospital. Jack's mobility was very limited since the stroke and he used a walking frame inside and outside of the house but could not walk far outside and was looking to purchase a mobility scooter. Although he could wash and dress himself, he received a lot of practical help from his wife who was his full time carer. Jack had experienced ill health before the stroke. He worked

as a foreman for a building firm and eight years ago he had had an accident at work and as a result he had to have his spleen removed which had affected his immune system and so he had to take medication. He had also had a hip replacement a few years ago which had meant he was using a stick to walk before the stroke. About a year before the stroke he had been diagnosed with carpal tunnel syndrome in one hand which affected the nerves and so he had limited movement in that hand. He also had high cholesterol and was taking medication for this and had recently experienced chest problems and was due to have a chest x-ray.

Jack and his wife Penny lived together in a council house. They and were from a large family and their children all lived nearby and visited them regularly. Jack's first wife had died due to Spina bifida and he had three children from his first marriage and another child who had passed away. Penny was his second wife and she was 20 years younger than him and in good health. They had been married for 30 years and had two children together and she had also had children from a previous marriage. Jack had 8 grandchildren.

ID15, 26.5.09: Molly and David

Molly (aged 75) had had a stroke in April 2007 while at home. At the same time her husband David (aged 81) aged had suffered angina pains which he felt had been brought on by the shock of seeing his wife have a stroke. He had previously had a heart attack and had a heart bypass operation. He called an ambulance for his wife then a relative also had to call an ambulance for him. Molly spent 6 days in hospital and received thrombolytic drugs and began to recover after this but they both said she's still 'not right'

after the stroke. Molly said that there was 'something wrong' with her right leg that meant it was difficult for her to walk. She was unable to do anything around the home apart from putting the washing machine on and had to use a stick to walk with outside and had trouble walking upstairs. They had had a stair rail fitted and a shower with a chair installed instead of a bath. David now has to do all the cooking and cleaning and give her a bit of help with getting dressed. They said that before the stroke they used to enjoy going out on coach trips at weekends but could no longer do this. David was able to walk and move around unaided but in addition to having a heart condition he also had impaired sight as a result of macular age-related degeneration.

Molly and David were White British. Molly had been a cook in a pub and her husband had worked at the local Docks. They had three children and eight grandchildren and a few great grandchildren, a few of whom lived close by and helped them out, particularly their daughter. They also had a neighbour who took them shopping regularly. They lived in a house that they had bought under the 'right to buy' scheme during the 1980s. Molly had lived in the area all her life and David had lived there for most of his life and they talked about how much the area had changed over this time. They had been married for 58 years.

ID16, 26.5.09, Ted and Rita

Ted (White British, aged 84) was crossing the street two and a half years ago to go to the post office when he collapsed with the stroke and was taken to hospital in an ambulance. He was now able to walk but only short distances, however he also had glaucoma and shortly after his stroke his

eyesight had further deteriorated so he was now registered blind. He used a white stick and was unable to go out alone. Rita (White British, 83) had also experienced much ill health, including severe arthritis and a heart condition that had lead to a heart attack three years ago. Ted was dependent on Rita for care mainly due to his poor eyesight but she talked about the difficulties she experienced in caring for him due to her own poor health. They had some help with shopping from a friend and they had four children and grandchildren who they saw quite regularly. They had been married for 65 years and lived in a council flat which they had moved into in the 1960s when it was newly built. They had experienced antisocial behaviour in the area over the last few years and felt the neighbourhood had deteriorated. Rita had worked as a cook and an office cleaner. He had worked in a printing press previously but had been unemployed receiving benefit before he had officially retired and received his state pension.

ID 17, 4.6.09, Sarah and Nelson

Nelson (Black African, aged 77) and Sarah (Black African, aged 76) were both originally from Nigeria and have lived in the UK for 36 years and have four children and grandchildren. Sarah had had her stroke a year ago. She was speaking on the phone to a relative in Nigeria while it had happened. She noticed that her speech had changed and her body was weak on one side. Her husband was at home and called the ambulance. She had been in hospital for a few months after the stroke. She was severely disabled and was unable to walk and unable to go out of the house and had help from carers who came four times a day. She could stand with the help of an electric chair that tilted up and then she could take a few steps using a walking stick. Since the stroke she was unable to go upstairs and so now

slept in a hospital bed in the dining room. She was unable to use the bathroom as there were steps down to it and so had to have washes instead of baths or showers. She was also unable to get to the kitchen and garden because there were a few small steps down to them.

They had been married for 60 years and lived together in a three storey Victorian terraced house. They had six children who lived nearby and they saw regularly. She had previously worked in a laundrette before retiring. Nelson had worked as a train conductor before he retired, was diagnosed with severe depression as a result of Sarah's stroke. He said it had been so upsetting to see her so disabled when she had been the person who looked after the whole family. He had been suicidal and was admitted to hospital with severe depression for 8 months while Sarah was still in hospital after the stroke. Towards the end of his stay in hospital he had come home at weekends but they had hardly seen each other at all over the 8 months.

ID18 24.7.09, Helen and John

Helen (White British, aged 84) had a stroke 11 years ago. She had collapsed when she tried to get out of bed and her husband John (White British, aged 85) called an ambulance and she was taken to hospital. After the stroke Helen was paralysed on one side but with the use of two sticks and the help of her husband she managed to walk a bit. However five and half years ago she had to have her leg amputated as she had gangrene as a result of diabetes. Since then Helen had to have help from carers during the day and the night but John also cared for her. She also reported suffering 'phantom' pains regularly when her stump was knocked. John also had health problems, including osteoarthritis and heart problems, and at the

time of the interview he had a leg ulcer that had become infected and so he was also using a wheelchair. Helen went to a day centre three days a week to give John some respite and enable him to do the shopping and other errands but he was currently unable to go out.

Until Helen's stroke they had been living in their family home in Hertfordshire but had since sold the house and bought a ground floor flat in London to be closer to their son and his family and to live in accommodation more suitable for Helen. Helen said she missed their home and the friends they had had there. They had been married for 46 years. John had a consultancy business that he still ran and Helen had helped out on the admin side of the business but had been unable to since her stroke which had meant they had lost business. Helen had previously worked as a church social worker.

ID19 15.9.09, Tony and Cathy

Tony (White British, aged 75) and his wife Cathy (White British, aged 74) were on holiday on a cruise ship to New York just over a year ago when Tony had a heart attack and was admitted to hospital there. When he came out and was staying in a hotel he had a stroke a couple of days later and his daughter and son flew out to New York. He was there in hospital for one month and then was flown back to St Thomas'. He was unable to move or speak at first but felt he had made good recovery since then. He is able to walk but not long distances and his speech has improved but he had mild aphasia. He took his time when speaking and sometimes got words wrong or muddled up. He said his heart problems effected his breathing. Cathy cared for Tony and did all of the cooking and house work, as she always had done. He had worked as a butcher before he retired several years ago.

Cathy had been a sales assistant before she retired. They had been married for 50 years and lived in a council flat. They used to go on holiday quite frequently before the stroke but they had not been on holiday abroad since his stroke due to concerns about Tony's health. They had two children and grandchildren who they saw quite often.

ID22, 5.10.09, Richard and Judy

Richard (White British, aged 83) had a stroke three years ago. He had come home from being at the pub and Judy (White British, aged 68) saw he was unwell and called a doctor who came and called an ambulance. Richard was in hospital for ten days. After the stroke he had difficulty walking and a year after this he was diagnosed with diabetes and emphysema which had limited his mobility even further so he now used a wheelchair when he was able to get outside. Prior to the stroke Richard had asthma, joint problems and a hereditary sight condition which meant he was registered blind. His wife was his full time carer who washed, dressed him and fed him. Judy had health problems herself including diabetes and circulation problems.

They lived in a high rise council flat on the 11th floor with lifts that were often out of order which meant they were unable to leave the flat. They had been on a list to move to more suitable accommodation for a while and felt 'angry' that nothing was being done to try to move them. In addition, Richard could not get into the bath so Judy struggled to wash him but the council would not fit a shower as they were on a list to move. Judy also talked about crime and antisocial behaviour in the local area.

They had been married for 32 years and it was a second marriage for both of them as Richard's first wife had died and Judy was divorced. Richard had worked as a delivery but his sight condition meant he had to stop work about 18 years ago. Judy had been an office administrator before she retired. They had no children but their neighbours and a niece and nephew helped them and they went to stay with Judy's sister quite regularly as she had a house with easy access for a wheelchair.

ID23, 6.10.09, Hilary and Adam

Hilary (White British, aged 79) had a stroke two years ago just after her and her husband Adam (White British, aged 80) had celebrated their golden wedding anniversary. She felt unwell and went with Adam to A&E on a Friday evening and talked about how unpleasant it had been waiting with 'lots of 'drunks and junkies'. She had problems with balance and her memory and says she gets more irritated but is unsure whether these problems are down to the stroke or old age. The only thing she needs help with is doing up her bra. Hilary has arthritis in her upper body and problems with her feet and so cannot go on long walks as they used to. They had been married for 52 years. Hilary previously worked as a textile designer and Adam previously worked as a judge (aged 80). They have two children, and one daughter lives in Australia but had recently visited them.

ID24, 1.11.09, Grace and Simon

Grace (Black Caribbean, aged 78) had her stroke 12 years ago and her husband Simon (Black Caribbean, 75 years) cares for her. She was sitting on the toilet and could not get up so had to phone Simon who was at work. He came home and called an ambulance and she subsequently spent two

months in hospital. She used a walking frame to get around the house but used a wheelchair outside although she said she rarely left the house. The council had moved them to more accessible ground floor flat since her stroke. She also had diabetes and arthritis which causes her pain. Simon was Grace's carer but he was not in very good health either and has 'problems' with his prostate. Grace was working as a care assistant in people's homes when she had the stroke but had to stop working after. Simon had previously worked as a hospital porter. They both said Grace had good and bad days. Grace spoke about how grateful she was to Simon for taking care of her and said that none of her six children would take care of her like he does. Her children came to see her but not that often as they do not live nearby. They were from Jamaica originally and had been married for 20 years and both had children from a previous marriage.

ID29, 22.7.10, Greta and Vas

Greta (German, aged 78) had a stroke just over a year ago, 12 days after celebrating her golden wedding anniversary with her husband Vas a Greek Cypriot, aged 79. She woke up and was unable to move her arm. Her husband wanted to call an ambulance but she wanted to see if she would improve so after washing and dressing she called her doctor who called an ambulance for her straight away. She spent the night in hospital on a mixed ward with men and was very upset by this. Since the stroke her balance had been affected and she walked with a stick. Her mobility had also been affected by two operations to replace her knee. The first one was four years ago, which 'went wrong' and led to her being 'very ill' and the other was nine months ago to correct the first operation. She now had to rely more on her husband as she was unable to do many chores around the house. She was

no longer able to go out alone, and she had previously enjoyed 'window shopping' and spending time with friends but could only now go out with her husband. However she felt grateful for the support of her husband and two sons and daughter-in-laws and grandchildren whom they saw regularly. They lived in a council flat and had lived in the UK for the majority of their lives. They had met in London and had been married for 51 years. Greta had worked as a nursery school teacher before retiring and Vas had been a waiter

ID30, 2.8.10, Tom and Nora

Tom (White British, aged 80) had a stroke 12 years ago followed by a second stroke and Nora (White British, aged 78) had had a Transient ischaemic attack (TIA) before Tom. Tom walks with a stick and is unable to walk far however he is still able to drive and they own a car. Tom had mild aphasia with slightly slurred speech, some pausing and problems with finding the right words. Nora has no physical impairments since her TIA but has memory problems. They were not able to go out as they used to since the stroke although they go twice a week to club where they dance. They have three children and grandchildren who live outside of London but they see them quite regularly and were shortly going on holiday abroad with their children. They bought their council flat under the 'Right to buy' scheme and talked about how the area had changed since they had lived there, particularly their neighbours. They had been married for 48 years.

ID 32, 10.8.10, Eric and Irene

Eric (White Irish, aged 79) lived with his wife Irene (White Irish, aged 77) who cared for him. He was working as a builder at the time of his stroke

fifteen years ago. One evening after he had come home from work he was in the bathroom and had turned the bath taps on but was then unable to turn them off. He shouted for help and his son, who had just come home, put him in the recovery position and called an ambulance. Eric was in hospital for 13 days and was partially paralysed on one side and had slurred speech. When he came home he was unable to walk very well and had physiotherapy. Gradually his mobility improved and was now able to walk down to the local shop for a newspaper. Because Eric was no longer able to work after the stroke this had affected them financially and they had had to claim benefits. A year after this he was diagnosed with diabetes and a year prior to the interview he was fitted with a pacemaker. Eric had also been diagnosed with asbestos poisoning as he had worked in the building trade all his life. They lived in a council house and had been married 50 years.

Irene had been a housewife and a carer for one of their daughters, now aged 44, who was born with dwarfism and also had numerous health problems as she was a diabetic dependent on insulin, was epileptic and had also had a stroke. Until recently Irene had been caring for both her husband and daughter who had been partially paralysed after the stroke but Irene had been unable to cope with her daughters' challenging behaviour and her daughter now lived in supported accommodation. They also had two other children and grandchildren who they saw regularly.

Appendix G: Coding grid for thematic analysis

Codes were organised under each overarching theme:

Stroke: stroke onset; stroke disability; stroke and social life; stroke and psychological/ emotional problems; stroke and caring; family support; stroke and relationships; stroke and independence; stroke care/ services.

Work and retirement: employment; value of work; experience of retirement; social aspect of work; financial.

Loneliness and bereavement: social loneliness; emotional loneliness; family; bereavement.

Housing and community: stroke/ disability and housing; community; local neighbourhood/ environment; neighbours; moving home; crime and safety, financial problems with housing.

The table below shows the number of times a code was recorded under each overarching theme for each participant/ couple during thematic analysis of the transcripts.

	Stroke	Work and retirement	Loneliness and bereavement	Housing and community
Ted (and Rita)	11	13	0	9
Patrick (and Betty)	17	8	0	10
Sheila	5	9	10	0
Sarah (and Nelson)	25	9	0	3
Paul	9	0	3	1
Grace (and Simon)	8	2	0	0
Gloria	8	0	3	2
Helen (and John)	8	2	0	0
Jack (and Penny)	41	3	0	0
Molly (and David)	21	2	0	6
Leonard	12	1	0	0
Martha	10	2	0	0
Tony (and Cathy)	16	3	0	0
Hilary (and Adam)	13	1	0	0
Gretal (and Vas)	23	1	0	0
Tom (and Nora)	8	1	0	3
Bob	13	12	0	0
Mary	14	10	0	0
Eric (and Irene)	15	7	0	2
Tim	9	8	0	0
Alfred	10	1	8	1
Rose	6	0	9	0
Derek	7	2	11	2
Joan	10	0	12	7
Delia	8	1	10	0
Richard (and Judy)	8	1	0	10
Ethel	10	2	4	12
<i>Total</i>	<i>345</i>	<i>101</i>	<i>70</i>	<i>68</i>

Appendix H: Coding grid for development of co-presentation types

The table below shows the codes that emerged from the analysis of the couple interview transcripts, organised according to type of co-presentation (underpinned by collaborative and conflictual narrative styles).

	Types of co-presentation		
	<i>‘United couples’</i> <i>(mainly collaborative narrative style)</i>	<i>‘Positive carer’</i> <i>(mainly collaborative narrative style)</i>	<i>‘Frustrated carer’</i> <i>(mainly conflictual narrative style)</i>
codes	‘Normal’ couple	Spouse as ‘natural’ carer	Burden/ challenges of caring
	Inter-dependence	Pride of carer/ spouse	Carer/ spouse frustration
	Strengthened relationship	Pride/ gratitude of stroke survivor	Poor health of spouse
			Other hardships
			Conflict re level of disability of stroke survivor
	Caring role*		
	Carer supporting stroke survivor’s presentation*		
	Self- reliant couple*		
		Dependency of stroke survivor*	
		Marital duty*	

*These codes applied to more than one type of co-presentation.

Appendix I: Conference papers and media resulting from this study

18th December 2013, Invited as a guest on Radio Four's 'Thinking Allowed' programme with Professor Laurie Taylor to discuss a paper I published based on my PhD findings in Sociology of Health and Illness (see Appendix J, page 358).

Radcliffe, E., Lowton, K., Morgan, M. (September 2011), '*Joint biographical narrative interviews: An innovative method for narrative research with couples*', European Sociological Association annual conference, Geneva (successful in my application for a bursary from the Foundation of the Sociology of Health and Illness)

Radcliffe, E., Lowton, K., Morgan, M. (July 2010), '*Co-construction of chronic illness narratives by older stroke survivors and their spouses*' as part of a symposium on 'Ageing, Identity and Coupledom', British Society of Gerontology annual conference, Brunel University (successful in my application for a bursary from the British Society of Gerontology)

Radcliffe, E., Lowton, K., Morgan, M. (Sept 2009) '*Co-construction of chronic illness narratives by older stroke survivors and their spouses*', British Sociological Association's annual Medical Sociology Conference, Manchester University

Appendix J: Published research paper resulting from this study

Co-construction of chronic illness narratives by older stroke survivors and their spouses

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Abstract Illness narratives have mainly focused on individual patients' accounts, and particularly those of people experiencing the onset of chronic illness in mid-life. However, a growing number of older people are spending their later life with their partner, with both experiencing complex morbidities. We examine the shared creation of meanings among older stroke survivors and their spouses and the implications for individual and couple identity. Joint biographical narrative interviews were held with 13 stroke survivors aged 75-85 and their spouses. The analysis examined both narrative content and narrative style. Three main types of co-presentation of identity were identified. The 'united couple' described couples who pulled together and emphasised their accommodation of the stroke and normality as a couple, despite often considerable disability, and was strongly underpinned by collaborative interaction in interviews. Caring relationships were distinguished as 'positive', involving self-reliant couples who took pride in how they managed and 'frustrated' in couples who emphasised the difficulties of caring and hardships experienced and were characterised by a conflictual style of narrative. We argue that joint interviews provide new forms of data that extend notions of how illness is lived and demonstrates how the marital relationship can mediate the experience of chronic illness and disability and its impact on identity.

Keywords: stroke, older age, chronic illness, narrative, joint interviews

Introduction

It is now well recognised that chronic illness can lead to a fundamental rethinking of a person's identity and biography, can affect relationships and material and practical affairs and may lead to the need to restructure future goals and priorities (Bury 1982). The conceptual

strategies that people employ in the aftermath of biographical discontinuity to create a sense of coherence, stability and order were described by Williams (1984) as narrative reconstruction, which involves narrativising chronic illness within the framework of one's own life history. As he explained, by assigning meaning to events that have disrupted and changed the course of one's life by linking up and interpreting different aspects of biography, one may 'realign the present and past and self with society' to achieve a redefined self (Williams 1984: 197).

The early focus on adults experiencing the onset of chronic illness in mid-life has since been broadened to locate and understand the influence of a diverse range of contextual factors on biographical disruption and to understand more fully the process of self-reconstruction. Studies have shown the significance of an individual's whole biography for the meanings they assign to chronic illness and processes of narrative reconstruction. This is illustrated by Kaufman (1988), Pound *et al.* (1998) and Sanders *et al.* (2002), among others, who demonstrate how individuals with various chronic conditions differ in their prior experience of crises and struggles associated with their age and socioeconomic background, which in turn shapes the meanings of new bodily disruptions.

Support provided by social networks is also identified as a contextual factor and resource that is often critical to the ways in which illness is lived and negotiated in people's lives. For example, Corbin and Strauss (1987) described spouses as playing an important role in the process of reconstructing the identity of people with various chronic illnesses, including stroke, with this often involving denying or minimising their failed everyday performances, for example, relating to personal care. However, most studies that consider the experience of chronic illness for other members of the patients' social network have focused on the demands of providing ongoing care to a person who is chronically ill (for example, Clark and Smith 1999, Scholte op Reimer *et al.* 1998) or how the experience of the chronic illness of a family member affects the life course of those around them (for example, Öhman and Söderberg 2004). These studies have all tended to rely on the individual interview, which as Lawton (2003: 35) notes in the context of qualitative work, may lead to particular types of narratives that tend to give less emphasis to the mundane, daily aspects of coping with the diseased body, although the physical aspects of living form the prime focus of the experience of chronic illness. Lawton (2003: 35) therefore called for a shift from the dominance of the single research interview and 'opening the door to a broader range of methods and methodologies to give access to a more broad-ranging and comprehensive picture of individual illness.'

We argue that the meanings and disruption consequent on chronic illness need to be considered together for both the patient and their spouse, rather than only for each party individually. An important way forward is therefore to conduct joint interviews with the chronically ill person and their partner, and to focus not only on what is said in terms of the content of talk but also to analyse the style of the narrative, in terms of how people talk about and present events. A few studies have employed joint interviews in examining experiences and responses to chronic illness but have mainly presented only the content of these joint accounts. These include a study of male coronary patients and their wives aged 30–70 years, which described how the marital relationship influenced men's styles of adjustment (Radley 1989); a study exploring couples' reactions to one partner's diagnosis of dementia (Robinson *et al.* 2005) and a study of adjustment to prostate cancer among couples aged 50–64 years compared to older couples (Harden *et al.* 2006). The largely descriptive accounts of such findings led Robinson *et al.* 2005 to suggest that further research should focus on couples' conversational interaction to gain a better understanding of the ways in which couples engage in the construction of joint chronic illness narratives.

Gerhardt (1991) emphasised the importance of focusing on the process of meaning construction in joint interviews with couples to gain insight into their joint interpretations of the 'marital reality' and shared social world. Her analysis of a single case study involved a joint interview with a married couple prior to the husband's coronary artery bypass surgery, which depicted the couple as striving together to present a unified front, creating an image of their relationship as competent and normal, despite experiencing chronic illness and financial hardship.

Moreover through their narrative about the low rate of sickness benefit, they presented themselves as an honest working couple abandoned by an uncaring welfare state, thus legitimating their claim to be a respectable family. A subsequent joint interview study by Manzo *et al.* (1995) involved male stroke survivors and their wives, and control interviews with men who had various other chronic conditions (for example, arthritis) and their wives. In contrast to Gerhardt's (1991) finding of a unified front, the authors found that stroke survivors lacked agency in the narratives as their wives tended to dominate, for example, by answering questions directed at their husbands and engaging in competitive storytelling, supplementing, correcting and contradicting their husbands' stories. However, the authors did not elaborate on this or on any other differences between the two groups.

As the compression of morbidity has not accompanied increasing life expectancy in later life in many countries across the globe (European Health Expectancy Monitoring Unit 2009), more older spouses will be living with long-term conditions as well as caring for a partner who also has complex morbidities (Pickard *et al.* 2000). Stroke is the single biggest cause of severe disability in the UK and is a common condition of older age. Each year 110,000 people in England and Wales have a first ever stroke, with 81 per cent of strokes occurring in those aged 64 years and over (Carroll *et al.* 2001). Our research is based on interviews with stroke survivors aged 75–85 years and their spouses, and thus focuses on a section of the older population that come within the policy category of 'frail older people' with physical and social care needs that can compromise their independence and quality of life (Department of Health 2001). This article builds on prior studies of couples' co-construction and presentation of joint biographical narratives and aims to explore how older couples used narratives to make sense of a stroke and how a stroke impacted on their relationship and identities, contributing towards an understanding of how older couples assign meaning to stroke through narratives (Williams 1984).

Methods

Data collection

Participants were recruited from the South London Stroke Register (SLSR), an ongoing population-based register recording the first ever stroke in people of all age groups in south London (Wolfe *et al.* 2011). At the time of recruitment to the interview study approximately 1800 living individuals were registered, 21 per cent (378) of whom were aged 75 years and over.

Eligibility criteria employed to identify potential respondents were: community-dwelling stroke survivors aged 75–85, at least 1 year post-stroke to ensure adequate time for participants to have adjusted to changed circumstances after an initial period of physical recovery (Mayo 1993), an abbreviated mental test score of seven or above to exclude those with severe cognitive impairment or memory problems and the absence of severe aphasia (communication impairment), recorded on the SLSR, although those with mild aphasia that may involve slurring or difficulty finding the correct word were included. In January 2009 to June 2010, 252 patients fulfilling these criteria were identified.

All stroke survivors on the SLSR give written consent to being contacted about participating in the research and a random sample of just over one-quarter (69) was sent an information sheet with an invitation to participate in an interview about the experience of their stroke together with their spouse or informal carer, if they wished. A follow-up telephone call was

made to those who did not return a reply slip. Most of those contacted by phone were happy to participate but found it difficult to return the reply slip due to their physical impairment. A total of 36 individuals were not contactable, reflecting the usual attrition in longitudinal studies, especially among older respondents with poor health (Chatfield *et al.* 2005).

Only seven stroke survivors declined to participate, mainly due to their ill health, with 26 consenting to participate either alone or with their spouse. This article reports on a subset of 13 joint interviews conducted with stroke survivors and their spouses as part of a wider study that also included stroke survivors interviewed alone. Permission was requested from both stroke survivors and spouses to participate in a joint interview and ethical approval was given by Bromley National Health Service Research Ethics committee.

Interviews were carried out by ER, a young researcher, and took place in participants' homes. Interviews lasted between 1 and 2 hours. They were based on Rosenthal's (2004) biographical narrative method that focuses on both the narrative content and its structure. They began with an open question asking the participants to tell the story of their stroke, with the aim of eliciting a detailed narrative indicating how couples made sense of the stroke, what meanings they attached to it, how they presented themselves as a couple and how they attempted to locate the stroke in their overall biography. The main narrative was uninterrupted but was followed by internal narrative questions that elicited more detail on themes discussed above, based on brief notes taken during the main narration. In the final part of the interview, external narrative questions were asked on topics of interest not previously discussed, such as the spouses' health.

Analysis

Interviews were transcribed verbatim and pseudonyms assigned. The analysis was adapted from Rosenthal's (2004) biographical case reconstruction method and involves two levels. First, data were analysed with a focus on the content of the narrative by exploring the events couples talked about, referred to as their life history and involved constructing a time-line to set out the temporal sequence of events before and after the stroke. Secondly, the analysis explored how participants selected the topics discussed during the narrative, how they interpreted the stroke and why they narrated their story in a particular way. This involved a detailed reading and coding of data according to Rosenthal's (2004) 'textual sorts':

- Argumentation: reasoning and theorising of general ideas; for example, a participant discussing why it is more appropriate for their spouse to care for them than a paid carer.
- Description: a sequence of text providing description; for example, the description of routines in relation to caring for a spouse.
- Narration: a linked sequence of past events related to each other using temporal and/or causal links; for example, discussion of the history of their ill health.

A further coding scheme was employed to analyse couples' co-presentation in terms of the structure of narratives and interaction that was informed by Veroff *et al.*'s (1993) scheme for the analysis of joint interviews. This involved coding each shift in speaker as one of six types of interaction. The first three types were categorised as collaborative styles of narratives and the last three as explicit or implicit conflictual styles:

- Collaboration: extending the idea of the spouse, questioning the spouse for information, answering questions that further the story or continuing a storyline that the spouse had previously begun.
- Confirmation: a statement of agreement, for example, 'I agree with you'.

- Confirmation-collaboration: an interruption that affirms the previous statement of the spouse and adds new material.
- Conflict: disagreeing with or interrupting the spouse with a negative response.
- Non-response: explicitly avoiding responding to the spouse's previous comment.
- Continuation: continuing the narrative without reflecting on the spouse's previous comment.

The approach to coding was agreed in discussion by all authors. Initial coding was carried out by the first author (ER) which was checked and verified by the other authors (MM, KL), with any discrepancies discussed in detail and consensus reached.

Characteristics of participants

Nearly all 13 couples participating had lived in the same property (mainly flats on council estates) most of their married lives. Most had previously held skilled manual or semi-skilled occupations, with just two couples (Helen and John, Hilary and Adam) who had previously engaged in professional occupations (Table 1). None of the couples lived with other relatives, although 11 couples had adult children. Six of the stroke survivors were women, with stroke survivors aged 75–85 years and their spouses aged 59–85.

Five of the stroke survivors were wheelchair users, three of whom rarely left their home. Three had mild aphasia. Tom and Sarah had slightly slurred speech and Tony had difficulty finding the correct words. All stroke survivors had multiple chronic conditions. Although the spouses were generally in better health, and all but one were able to walk unaided, eight had at least one chronic condition. Only two stroke survivors (Sarah and Helen) received assistance with their personal care from paid carers.

The findings section first discusses the couples' styles of narrative and then describes the different forms of co-presentation of identity that we refer to as united couple, and positive and frustrated carers.

Findings

Styles of narrative

Couples frequently began their narrative with a focus on the stroke event and then discussed in more detail living and coping with stroke in the present and near future. The interactional dynamics between the couples frequently shifted throughout the interview, with spouses often taking it in turns to narrate, sometimes talking between themselves while trying to negotiate their narrative, and at other times one spouse would take a more dominant role than the other.

Couples' narrative style emerged as either predominately conflictual or collaborative, based on the frequency of the Veroff codes applied to each shift in speaker. The speech of the collaborative couples mainly built on each other's narratives, with a high degree of confirmation and confirmation-collaboration codes and very little conflictual interaction. The couples with a mainly conflictual style of interaction engaged in some collaborative interaction but also often disagreed or interrupted the spouse with a negative response and frequently continued talking without taking into account what their spouse had said previously (identified as continuation), indicating an implicit conflictual style. Non-response codes did not occur frequently. Hearing problems, common in older age, appeared to contribute to most of the non-response rather than this being intentional.

Table 1: *Participants' characteristics (stroke survivors in bold)*

<i>Pseudonym</i>	<i>Age</i>	<i>Years married</i>	<i>Years post-stroke</i>	<i>Previous occupation</i>	<i>Ethnicity</i>	<i>Main health conditions (other than stroke)/mobility</i>
Patrick	85	58	1	Van driver	White Irish	Hearing impairment, walks unaided
Betty	83			Bookmaker's cashier	White Irish	Osteoporosis, walks unaided
Jack	79	30	1	Builder	White British	Walking frame and wheelchair user
Penny	59			Housewife	White British	Walks unaided
Molly	75	58	2	Housewife	White British	Walks short distances unaided
David	81			Shipyard worker	White British	Heart condition, sight impairment, walks unaided
Ted	84	65	2.5	Factory worker	White British	Severe sight impairment (registered blind), walks unaided
Rita	83			Cook	White British	Heart condition, severe arthritis, walks unaided
Sarah	76	60	1	Laundrette worker	Black African	Mild aphasia, wheelchair user
Nelson	77			Train conductor	Black African	Depression, walks unaided
Helen	84	46	10	Church social worker	White British	Diabetes, wheelchair user
John	85			Business consultant	White British	Osteoarthritis, heart condition, wheelchair user
Tony	75	50	1	Butcher	White British	Heart condition, mild aphasia, walks short distances unaided
Cathy	74			Sales assistant	White British	Walks unaided
Richard	83	32	3	Driver	White British	Severe sight impairment (registered blind), diabetes, wheelchair user Diabetes, walks unaided
Judy	68			Administrator	White British	
Hilary	79	52	2	Designer	White British	Walks short distances unaided
Adam	80			Judge	White British	Walks unaided
Grace	78	20	12	Home carer	Black Caribbean	Walking frame and wheelchair user
Simon	75			Hospital porter	Black Caribbean	Prostate problem, walks unaided

Table1 (Continued)

<i>Pseudonym</i>	<i>Age</i>	<i>Years married</i>	<i>Years post-stroke</i>	<i>Previous occupation</i>	<i>Ethnicity</i>	<i>Main health conditions (other than stroke)/mobility</i>
Gretal	78	50	1.5	Nursery school teacher	German	Uses walking stick
Vas	80			Waiter	Greek Cypriot	Walks unaided
Tom	80	48	12	Warehouse worker	White British	Prostate problem, mild aphasia, walks short distances unaided
Nora	78			Cook	White British	Transient ischaemic attack, walks unaided
Eric	79	50	15	Builder	White Irish	Diabetes, walks short distances unaided
Irene	77			Housewife	White Irish	Walks unaided

These collaborative and conflictual styles of narrative underpinned the three types of co-presentation identified in relation to the content of the narratives. These different forms of co-presentation are described below.

Co-presentation of identity

United couple: Presentation as a united couple was evident in aspects of most couples' narratives but emerged very clearly in six (Jack and Penny; Molly and David; Helen and John; Patrick and Betty; Gretel and Vas; and Tom and Nora). Although the stroke often initially caused great disruption to their lives, these couples presented themselves as morally competent, self-sufficient couples who had jointly adapted to varying levels of disability as a result of the stroke. Their narratives showed that together they were currently managing life with a stroke as well as other illnesses and hardships, and often minimised the impact of the stroke. Their narrative style was largely collaborative, characterised by the frequent use of 'we' and by confirming and collaborating talk through repetition and overlapping to finish each other's sentences in ways that emphasised their partnership. One example is Molly and David. After Molly's stroke David had to help her with aspects of personal care such as getting dressed and he took on more of the household chores, despite his own heart condition and problems with his eyesight. However they presented themselves as a normal couple who engaged in activities as other retired couples did. As David observed, 'There a lot a people 'alf our age who're worse off than us, ain't they, you know what I mean', while Molly supported this adding that they were soon to go on a short holiday. To continue the storyline, each built on what the other had said, as illustrated by the following extract that focuses on David's past experience with the anticoagulant drug warfarin, a drug they both take.

M: We both go to the (warfarin) clinic together.

D: The only trouble is it don't 'alf alter your blood you know, that warfarin.... I 'ad a lump come up didn't I, ah you wanna hear another problem?

M: He had a lump in his jaw.... Never stopped bleeding.

D: And eventually they can't stop the bleeding so I get them tablets, I got huh some acid tablets, they didn't stop it so James er from the er what was it?

M: From the warfarin clinic.

D: From the warfarin, he phoned up some professor geezer and he said er double it up but then we had another plan what we should have done in the first place, keep chewing on lumps of cloth, trying of course to stop the bleeding. I was waking up in the morning and my tongue was like that.

M: Yeah it was horrible, wasn't it?

D: Cough, oh my god, frighten you. I think we managed to sort it out ourself Molly didn't we [laughs]. (Molly, aged 76, stroke survivor and David, aged 81)

In some cases united couples described their relationship as having been strengthened through their shared experience of the stroke. For example, Gretel, a stroke survivor, described how she could go out of their high rise flat only if her husband (Vas) was with her due to her risk of falling. Rather than talking about being dependent on her husband she presented the two of them as 'a team' who were dependent on each other, demonstrating a sense of agency and autonomy as a couple. Throughout their narrative they engaged each other in a confirming and collaborating form of interaction, agreeing with one another and building on each other's

narrative:

G: We have always been a loving and caring couple, I can say that without hesitation but obviously our relationship has changed because chores in the house I would do without thinking about it. I am restricted doing so ...

V: Now I've got to do it [laughs].

G: You don't have to, but you do it [laughs]. So our relationship has deepened. No? V: Oh absolutely.

G: We are more, as I said before we have always been close, very close and we are well known among friends and family, they say with a couple like you, one doesn't fight very often ... it was destiny that I came from Germany and Vas came from Cyprus, we met and lived happily, happily ever after ... Both of us we are a team. We've always been but since I had the stroke –

V: We've always been, now it's more, because she needs me. We are more close than ever.

(Gretel, aged 78, stroke survivor and Vas, aged 80)

There were variations among co-presentations as a united couple. Tony and Cathy's narrative differed markedly in structure to that of the others as, although Tony had made a good physical recovery from his stroke, his aphasia meant he spoke in a slow, stilted manner and had some difficulty finding the correct word. As the narrative progressed Cathy began to take a more dominant role by prompting, correcting or answering for Tony and finishing his sentences. Tony would also ask Cathy for confirmation or support to continue the storyline, shown here in the context of his recounting the history of his stroke:

T: I, we was on the boat, hh and um, no I had heart attack on the boat and I got to New York and they took me off the boat into the hospital and they fitted me with a pacemaker and it's, how many days after

C: It was about 4 days after you had a pacemaker put in, he had the first stroke...

T: Affart from the s, speech, um, that's all the result of the stroke, uh I don't C:

Yeah I mean obviously you're not as agile now as what you was before.

T: Huh now and again I get, um, leg, leg, left leg seelsa bit funny at times but ur I get about on that.

C: Not your left leg, your right leg. T:

Uh right leg.

C: Because it was all down the right side. T:

Right leg.

C: where it was affected, yeah, yeah.

T: Sometimes it feels a bit funny but apart from that. A, a all er the troubles that I uh had is the breathing problems.

C: 'e has, he's made a fantastic recovery. You know, as I say, no one thought he was going to come through it, even the doctors was so surprised.

(Tony, stroke survivor, aged 75 and Cathy, aged 74)

Together the couple sought to minimise the impact of Tony's aphasia by using humour, enabling them to display an image of a normal united couple. For example, Cathy joked about her own hearing problems saying, 'he can't get his words out and I can't hear, we're a pair well matched!'

Although Cathy assumed a dominant role in the narrative she appeared to use this to construct a socially acceptable presentation as a united couple, with Tony actively

collaborating and inviting Cathy to take this role through his requests for confirmation from her at different points throughout the narrative. This could therefore be regarded as forming 'scene support', rather than Shakespeare's notion of 'scene stealing' by a dominant individual in the dyad (Shakespeare 1993). This narrative form did not occur in the co-constructed narratives of the other two participants with aphasia, possibly because they did not experience problems with word-finding as Tony did, as well as reflecting differences in individual personality.

Carer relationships: 'positive' and 'frustrated' carers

All couples brought up caring for their spouse following stroke as an unprompted part of their narrative. However, in some narratives the notion of a spouse as carer was an image that dominated the couples' co-presentation. This is illustrated by Jack and Penny, who together engaged in a confirming-collaborative narrative to present themselves as a self-reliant couple, with Penny willingly caring for Jack who had very limited mobility and required the use of a walking frame and wheelchair. Together they presented Penny as a positive carer, with Jack describing how well he was looked after and Penny emphasising that it would be difficult to seek assistance from a paid carer due to Jack's stubbornness, implying that she was the best person to care for him. This was supported by Jack who emphasised Penny's 'natural' role as his carer:

J: Penny's be, been brilliant... In hospital I didn't like them cleaning me and washing me ...If the wife's doing it, I mean, we've been together alotta of years and it seems more of a natural thing. But to have a stranger doing it, it's, to me that weren't on ... The thing is I've always been a very, very stubborn person.

P: Oh yes, very stubborn.... Well I know basically how, what he likes, what he don't like, you know, and I'm here all the time.

J: She knows how moany I can be.

P: Oh yes, I don't think a carer could take it, you know. They'd be running away [laughs]. J: She lays the law down ... but really when I sort of think about it, I, she's right.

(Jack, stroke survivor, aged 79, and Penny, aged 59)

Whereas this extract accords with the notion of women as being 'natural' carers, it was not only wives who were presented as positive carers, as illustrated by Grace and Simon's narrative:

G: Not one of my children would ever do me, open their hearts to me as how Simon... He wash, he cook, he iron, he clean, he do everything believe me... He's not well as well so I don't want to see him lay down 'coz if he lay down I will suffer.

S: ... I'm not too well really ... I've got this prostate [problem] ... life have to continue.

G: He have to do everything, he have to put my clothes on for me. So it is really bad. Really, he, he wash me. So I am really bad. I'm not hiding it and I can't, God give me him for a reason.

(Grace, stroke survivor, aged 78 and Simon, aged 75)

Other spouses similarly talked about their caring responsibilities with a sense of pride. For example, Betty related that her general practitioner told her that by nursing her husband 'in

the right and proper way' when he had pneumonia recently she had 'saved the hospital hundreds of pounds'. Similarly, Judy described herself as a good nurse and reported that while visiting Richard in hospital after his stroke a nurse told her that she admired the way Judy cared for her husband. However whereas Judy described her positive caring role, this was accompanied by aspects of a carer who was dutiful but 'frustrated', as shown by their relationship and style of interaction. This notion of a frustrated carer also characterised the account given by Rita. Judy and Rita were both very keen to tell their own story of their husband's stroke in terms of the disruption it meant to their own lives due to the high level of care their husbands needed and also both husbands' severely limited eyesight, which had led them to be registered as blind (Table 1). This is illustrated by the following extract in which Judy engaged in a conflictual style of narrative, interrupting her husband and seeking to present herself as the dominant narrator who will tell the 'correct' version of the story:

J: He used to go down to the pub every day, you know, to have a couple of pints and he just come barging in one day and through the door and he said, 'I can't walk'. And he just got near the chair and I had to grab 'im, he just fell to the floor nearly, and I just got him in a chair. So I called our doctor and she came out. She was a French doctor at the time, and er she said, 'Oh, you've had a slight stroke Mr Finch and she' –

R: She sat there, says, 'you're having a stroke'

J: Yeah, yes, well we know that Richard. I'm just giving her [the researcher], I'm telling her exactly what happened. [Addressing the researcher] Sorry, I'm not being rude to him, but he does this every time. (Richard, aged 83, stroke survivor and Judy, aged 67)

Similarly Rita who presented herself as a dutiful but 'frustrated' carer took a dominant role in her narrative with Ted:

Rita: I've had 'eart attack myself, well I've had three stents put in as well you see so, obviously I can't, when he falls I can't pick him up. And I've also got arthritis all over me back and I just can't whatsaname so I can't cope with him ... I have to cut his food up for 'im and 'cause, you know, he can't cut his food up properly and he can't see what's on the plate and that goes everywhere ... He can't see the steps when he goes out like, you know. When he goes out he's got his stick, his white stick and that but I was out one afternoon, he'd gone across the shops on his own, you see so he can't be trusted.

Ted: I've gone across to the shop on the crossing.

R: That doesn't make any difference, whether you're on the crossing or not because you can't see ... I tell him he's not to answer the door when I'm not here. So but I think on the whole his life has completely changed. (Ted, stroke survivor, aged 84 and Rita, aged 83)

A further variant of the carer relationship was provided by Sarah and Nelson. This narrative focused on Sarah's role in caring for Nelson 'day and night' during their 60 years of marriage in view of his depression and mental health problems, and Nelson's inability to act as a carer for Sarah, who was left severely disabled and housebound after her stroke. The couple talked about Nelson's severe depression happening as a direct result of Sarah's stroke and how he spent 8 months in a mental health unit from the week she was discharged from the stroke unit, meaning they were living apart during that time. Although Sarah had slurred speech she took the dominant role, talking about how she coped with disability and how she relied on paid

carers and her children. Their narrative differed from those of Ted and Rita and Richard and Judy as the conflictual interaction was less explicit with minimal response from Nelson. Underlying tension and conflict between Ted and Rita, Richard and Judy and Sarah and Nelson emerged in the structure of their narratives, largely dominated by themes of illness,

profound disability and the need for a high level of care. Various health problems experienced by both the stroke survivor and their spouse appeared to be making their lives very difficult. The couples' conflictual narratives therefore appeared to be at least partly driven by the practical realities and hardships they were experiencing in coping with stroke and other ill health at the time of the interview and may have been influenced by the relative recency of the stroke, with interviews at 1–3 years post stroke.

Discussion

This study has extended notions of how illness is lived in terms of older couples' interpersonal relationships and daily lives and identified three main types of co-presentation of identity from joint interview data. United couples displayed couples as pulling together to cope with the stroke and other disabilities, strongly underpinned by the couple's collaborative interaction. Positive carer presentations were similarly underpinned by a collaborative style of narrative as part of a display of self-reliance as a couple, with both a united couple and positive carer characterised by a stoic attitude. Although many of these stroke survivors were physically dependent on their spouse, thus lacking personal autonomy, their co-presentation demonstrated a sense of agency and autonomy as a couple. In contrast, the frustrated carer presentation was mainly underpinned by conflictual interaction that may reflect both the prior marital relationship and the practical realities and hardships experienced by older spousal carers in coping both with their own health and their spouse's disability.

Narratives are likely to vary according to age, gender and class, reflecting couples' particular life experiences and circumstances. In terms of gender, husbands and wives appeared to engage equally in the construction of the narratives, with both using similar collaborative or conflictual forms of interaction. This supports the findings of Seale *et al.* (2008) that traditional gender differences in terms of linguistic style and topic content, as described by Coates (2004), are reduced in joint interviews. However during the three mainly conflictual narratives the wives tended to dominate, reflecting Seale *et al.*'s (2008) findings that women's perspectives are more prominent in joint interviews as they speak significantly more and more often than men. However our interviews, as with Seale *et al.*'s (2008) study, focused on health-related matters for which women are commonly regarded as being the most appropriate reporters. In contrast to these wives' dominant narrative role, West and Zimmerman (1998) showed how men use interruption as a way to dominate naturally occurring conversational interaction with women (including conversations between couples), and drew parallels with their earlier findings based on parents' domination of conversations with their children.

The dominance shown by women in our study's mainly conflictual narratives may have reflected the general nature of these couples' marital relationships in which the wives took a dominant role in conversational interaction with their husbands. However, their relationships may have changed over time and been shaped by the men's ill health and high level of physical dependency, with the nature of the marital relationship known to be influenced by illness and disability (Walker and Luszcz 2009). This is suggested by the way in which both Judy's and Rita's accounts tended to portray themselves as frustrated carers coping with a high burden

of care and to infantilise their husbands, who were both registered as blind. By applying a novel method to analyse joint biographical narrative interviews our research has enabled an in-depth understanding of older couples' relationships and how they adjusted and accommodated to the considerable impacts on their lives of stroke and other chronic illness and disabilities. For example, it was notable that stroke survivors were often able to demonstrate agency by drawing on their autonomy as a couple, despite being physically dependent on their spouse. We also highlight the complexities of spousal caring among older people, especially as couples are more likely to rely on a spouse for social, emotional and physical support as more of them survive into old age (Pickard *et al.* 2000) and wider social support networks shrink. The findings have implications in terms of addressing the needs of older spousal caregivers, particularly in relation to the three couples presenting mainly conflictual narratives. These frustrated carers appeared to be struggling to cope with the impact of their partner's stroke and other chronic illness, as well as their own ill health, pointing to a need for practical and emotional support. As Dean and Thomas (1996) note, stereotypical views of old age tend to homogenise older people and thus their role as informal carers, whereas our data demonstrate that older spousal carers are a diverse group among themselves, with differing levels of need; and indeed, many of our participants would be unlikely to regard themselves as carers. This heterogeneity among older couples needs to be reflected in the context of providing health and social care to an ageing population.

Our analytic approach was based on the premise that the couples were participating in a social performance during the interviews and the narrative data were therefore analysed as shared meanings created through social interaction, or social constructions. The narrative analysis method was systematic and practical to ensure transparency, rigour and validity (Atkinson 1997). Although Rosenthal's (2004) biographical narrative interview method aims to provide participants with as much freedom as possible to structure their own narratives, the questions asked, how they were asked and which spouse they were directed to inevitably had some influence on the construction of the narratives. The significant age difference between the participants and the younger researcher may have also influenced the couples' co-presentations. As Rozario and Derienzis (2009: 551) suggest, the much younger researcher may have 'served as an external reminder of their age, and their representations of themselves might be seen as reactions to this reminder.'

Joint interview data are constructed by both participants in a continual process of negotiation and can therefore be viewed as a 'particular form of "institutional talk"' (Seale *et al.* 2008: 126). Jointly interviewing those who are chronically ill and their spouse may make participants feel more comfortable; additionally it may be more acceptable for the chronically ill participant to take rests during the interview (Morris 2001), while for aphasic participants, having a spouse to support their narrative construction may make participation easier. Much previous work based on joint interviews with couples would have benefited from moving beyond a purely thematic approach with minimal interpretation of the co-construction of narratives, while further studies are required to examine variations in the content and style of interaction that may occur at different stages of managing the demands of chronic illness and disability and for different age, socioeconomic and cultural groups.

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